

# *Traumatic Brain Injury: A Guide for Caregivers of Service Members and Veterans*



Becoming a Family Caregiver for a  
Service Member/Veteran with TBI

Module 3







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*An electronic version of this Guide can be found at the following Web address:  
[www.traumaticbraininjuryatoz.org](http://www.traumaticbraininjuryatoz.org)*

# Module 3 Summary

You play an important role in the recovery of your service member/veteran with TBI.

You may be a spouse, parent, sibling, or friend. Your job as a caregiver may include being a:

- case manager
- advocate
- benefits coordinator
- health care provider.

All of these roles may be new to you.

This module focuses on helping you, the caregiver. It offers tips on how to get organized and get help. It also suggests ways to take care of yourself while caring for your family member.

Some of the main ideas in this module are:

- Get to know the members of the health care team and the case managers. They can and will help you during the hospital stay, during recovery, and when your service member/veteran comes home.
- Keep health care and military information about your service member/veteran in a notebook. Being organized helps you feel less stressed.
- Talk about your needs and the needs of your service member/veteran to others (advocacy).
- Take care of yourself first, so you can take care of your service member/veteran.
- Take time and be honest when helping children and other family members cope with TBI.
- Allow your friends and family to build a support network to help you. Ask for help. No one can do it alone.
- Plan for some time off. Respite care and day care programs are valuable resources to you and your service member/veteran.
- There are ways to balance work and caregiving through Family and Medical Leave and other means.
- There are key legal issues to address to protect your family and your service member/veteran.

Much of the information in this module was guided by family caregivers of service members who suffered a TBI.





*You are an important team player in the active recovery of your service member/veteran with a TBI.*



## Starting Your Caregiving Journey

You are starting out on an important journey in your life--becoming a family caregiver to someone who has a traumatic brain injury (TBI). A caregiver like you can help your service member/veteran recover as fully as possible.

**Caregiver:** Any family or support person(s) relied upon by the service member or veteran with traumatic brain injury (TBI) who assumes primary responsibility for ensuring the needed level of care and overall well-being of that service member or veteran.

For the purposes of this Guide, “family” or “family caregiver” will include spouse, parents, children, other extended family members, as well as significant others and friends.

You may be feeling overwhelmed, angry, or scared. You may also feel alone and worn out by your new role.

Please learn about TBI. Take good care of yourself while caring for your service member/veteran. Keep hope alive during your journey toward recovery.

### What is the Course of Recovery?

Recovery from TBI is a gradual process. It may take weeks, months, or even years. Those with a TBI may need assistance for weeks to months. Some will need help for the rest of their lives. For those in a minimally conscious state, some may need long-term care outside of your home.

Each TBI is different. Each person needs different help and support from his or her caregiver.

### How Important is My Caregiving?

Caregivers play an important role in recovery. In fact, many people who work with TBI patients believe that having a caregiver just like you is one of the most important aids to recovery. Your job is to actively follow the treatment plan and offer guidance and help to your injured family member.

*Few families know what to expect after a service member/veteran receives a brain injury.*

*The information in this Guide will help you cope with your new role as a caregiver.*

Learn all you can about TBI. The following suggestions may help you:

- Use this Guide. It provides tips on how to be a good caregiver.
- Ask questions of the doctors, nurses, and other health care providers.
- Classes or online discussion groups may be helpful.



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*"You're the person who knows your family member best. That's what my neurologist told me. He said you're going to have to help us here because you know him best. You have to let us know if he's hurting, if he's not hurting, if he's waking up, because you know him best. So you're going to really have to help us here to know what's going on with him because he can't tell us."*

- Denise G.

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# Keeping Important Paperwork Together

*"Try never to despair. I know that everybody has moments and walls or the black day that you feel is the end of the world. The truth is that each day is a new day and you can look for the little moments."*

- Lee Woodruff, wife to newscaster Bob Woodruff who sustained a TBI while covering Operation Iraqi Freedom. Co-author with her husband of *In an Instant: A Family's Journey of Love and Healing*

**Rehabilitation** isn't necessarily about getting back to "normal." It may be about creating a new "normal."

You are providing a very important service to someone you care about. This chapter is about organizing your service member/veteran's medical and military records to make your caregiving job easier. You are not alone. Health care providers and other professionals are there to help you every step of the way.

*Rehabilitation means re-learning how to do everyday things.*

## How Should I Organize Medical and Military Records?

The more organized you are, the better. Being organized will help you:

- have more control
  - making decisions
  - having access to accurate information
- reduce your stress
- have all the care-related information you need in one place
- keep all the important documents needed for the Medical Evaluation Board (MEB) and Physical Evaluation Board (PEB) (see Module 4, Chapter 12).

### Organizing Information

A notebook helps a family member with TBI and his or her caregivers keep information they need together in one place. See the Caregiver's Companion provided with this Guide. The Companion will help you get started organizing your paperwork.

You may end up with several notebooks or folders like this. You should keep all medical information. You may even want to enter information into a computer file.

*Keeping a notebook about your family member's health care helps you stay organized.*



*"I developed my own filing system. Every time Jason gets a new medication, they give you a medication list that tells you the side effects and all of that. That goes in the medication information slot. Every time he had surgery, that information went into the surgery history slot. I actually took it upon myself to create a file on the computer of every surgery that he's had, what they've done, and the date. I documented every seizure that he's had. I carry that with me so that when someone says, 'Well, what are his surgeries? We need a list of his surgeries. We need a list of his seizure history'--it's right there. I give it to them.*


*I have a filing system for his orders. I have a file for his profile. Definitely keeping everything organized early on is helpful, and keeping a daily journal of what's happening, who you're talking to, whether he had a good day or a bad day, he started eating today, he took 10 steps today. I have a list of every single appointment that he's gone to from day one, and I just keep everything. He has his own file cabinet."*

- Sandy M.

The notebook could include sections for:

- **Personal information** – This includes important facts, such as your service member/veteran's Social Security number, military service record, emergency contacts, and allergic reaction to medications.
- **Military service papers** – Keep copies of military service records, etc.
- **Medication log** – Write down all the drugs taken, dosages, dates, side effects, and problems. There is a blank form at the end of this chapter that you can use.
- **Medical reports, tests, scans** – Ask for copies of all reports, scans, and tests, and file them in this section of the notebook. Put CT and MRI scans of the brain on a compact disk (CD). Keep these to share with future providers.
- **Notes and questions** – Include a three-hole punched notepad in your notebook. You can use it to take notes and then insert the sheets in the right sections.



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- **Resources and information** – This is the place to keep all the forms and information you have received at appointments.
  - **Calendar of appointments** – Use a calendar with enough room to write all of your appointments.

You may want to keep another notebook or file with the records needed to apply for medical and family benefits or the Medical Evaluation Board/Physical Evaluation Board (MEB/PEB). (See Module 4 for more information about the MEB/PEB.)

This file will help when you apply for financial aid, a job, or more medical care. When you are not using this file, keep it in a locked place to keep it safe.

This file could include:

- Social Security card, military records, and insurance cards
- Power of Attorney
- driver's license, birth certificate, marriage certificate
- school and work records
- tax returns and assets.

## Paying Bills

If your family member with TBI can no longer handle paying the bills:

- Consider changing the contact name on financial accounts to your name or the name of a person who has Power of Attorney.
- When accounts are in joint names or in the name of the person with TBI, it may not be easy to change names on financial accounts. You may need to obtain legal guardianship. (See Chapter 9.)
- Consider online banking and bill paying.



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*"I observed another wife... she had binders that were for the medical stuff or for things like the Power of Attorney or different documents that you would need. Then there were different binders for therapy, because you do get worksheets, especially for speech therapy. I'll usually carry one binder if I travel. I'll bring all the special information with me on the airplane.*

*Also, the list of medicines is really important. A lot of information is sent on e-mail. I keep a separate folder for Army e-mails in my e-mail account so I can always go back and look.*

*In the beginning, I bought a book to put business cards in. You meet so many people. People hand you a card, in case you need anything, and some of those people I've actually called because I do need things. You can buy the book at an office supply store that holds up to 100 business cards. I have three of them full now, after a year and a half.*

*I carry these little books with me so I always have phone numbers. I've also put phone numbers in my e-mail contact list—I try to put them in two different places, so I don't lose things."*

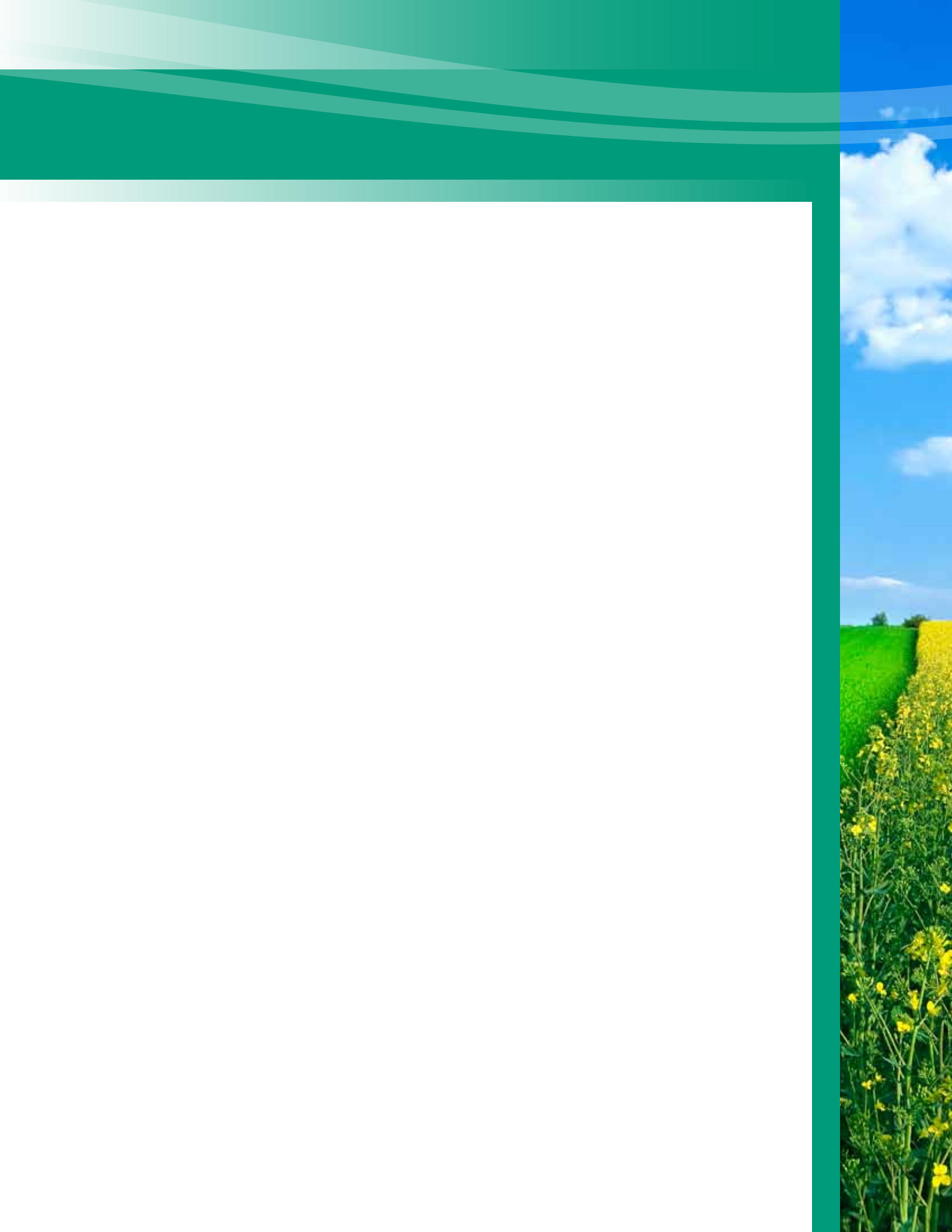
- Patty H.

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## Medication Log

[illegible]





## Becoming an Advocate

*"As caregivers for my brother, my family and I were his voice when he could not speak. This could be anything from hanging signs in his room that reminded nurses and therapists where Ethan was missing his skull, to helping with rehab, to filling out paperwork, to going to JAG officers to discuss Power of Attorney issues. Every day, seven days a week, it became our lives. It's easy to fall into a groove. Sometimes that groove is comforting, but sometimes it makes you complacent. It's important to stay on top of the situation and not take things for granted.*

*As a caregiver, you know your loved one and his or her treatment plan the best. You can easily recognize when something is working well or when something is wrong. Never hesitate to acknowledge improvement or voice a concern, always ask questions about a procedure with which you are unfamiliar, and continually seek out benefits to which your loved one is entitled. Information is not always volunteered to you; if you don't ask, you might not receive.*

*Being a caregiver means being an advocate. You've already committed yourself to caring for your loved one; it comes naturally that standing up for him or her should be part of that care."*

- Liza B.



As a caregiver, you may find yourself in situations where you need to **advocate** for your service member/veteran with TBI or for yourself.

But you may be saying to yourself,

- "What me? Advocate? I've always been the quiet type. I'm not comfortable demanding anything from anybody," or
- "I don't have the education or authority to talk back to those who hold positions of authority," or
- "I'd rather be dead than have to speak in public."

Advocacy involves basic communication skills:

- listening to what other people have to say, and
- talking about what is important to you.

*You are an advocate when you speak out on behalf of someone or something that you believe in.*

*Advocacy is a form of problem solving, something that you probably already do every day in your own life.*

*Learning how to talk with health care providers is part of being a good advocate.*

*DoD is the Department of Defense.*

*VA stands for the Department of Veterans Affairs.*

You can learn to build on the **problem-solving** skills that you already have to become an advocate.

Generally, there are three types of advocacy:

- **Self-advocacy** – understanding and effectively communicating your own needs to others
- **Individual advocacy** – speaking out on behalf of your service member/veteran with TBI
- **Systems advocacy** – attempting to change government, organization or agency policy, rules, or regulations.

Advocacy is all about:

- knowing what you want in a situation
- getting the facts
- planning your strategy
- being firm and persistent
- maintaining your credibility.

Let's look at situations where your advocacy skills are needed.

## How Do I Advocate to the Health Care Team?

Becoming an advocate about TBI begins when you first meet the health care team who care for your injured service member/veteran.

Try to learn as much as you can from them about TBI and the treatment plan for your service member/veteran. Try to learn as much as you can about the **DoD** and **VA** medical systems and how to use these services. (See Modules 2 and 4.)

This is all part of getting the facts. Understanding the facts will make you communicate better with everyone.

Tips for advocating with health care providers:

- If you have problems or concerns with the care your service member/veteran is receiving, identify what you think is needed.
- Be specific.
- Talk about your service member/veteran's needs directly to the members of the health care team. Early morning is when doctors make their rounds, visiting patients. This may be the best time to talk to them.
- Be clear and be firm about what you need.



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*"Basically you have to take the well-being of your loved one into account or you'll get lost in the shuffle. There's a bunch of people here in the hospital and they're injured. If you don't keep up with your loved one's therapy, you will get lost in the shuffle because there are so many needs to be taken care of.*

*You have to be your own advocate and the advocate for your loved one, and make sure he's getting everything he needs."*

- Emily S.

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- Be persistent and firm, but in a cooperative manner. If you don't get a response right away, keep asking.
- If this approach does not seem to work, contact the Ombudsman or Patient Advocate at the service member/veteran's health care facility.
- Try not to be confrontational.
- Come prepared with a list of your questions when attending care conferences. Take notes during meetings or ask a friend or another family member to do this for you.
- Do not tell someone how to do his or her job. It seldom works. Instead, talk to the person as a concerned family member and explain your worries calmly.
- Remember, the health care providers are in charge of your loved one's care. You will be talking with them on a regular basis.
- Work with the health care providers. Remember, they are well intentioned. They might not know the exact needs of your loved one yet. You are telling them.
- Give reasons for health care providers to give special care to your family member. Tell them about his or her stories and personality traits. If they get to know your loved one, they may be more alert to his or her care.
- Often, if you let health care providers get to know you, they will listen to your concerns with better understanding.



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*"Try to keep a cool head when you are speaking on behalf of yourself or others. Know what you're talking about. If you don't, then ask questions and be willing to learn. The more you sound like you're angry or 'just complaining,' the less others will listen. If you are receptive to someone, often he or she is receptive back. This is what maintains a level of respect and credibility."*

- Liza B.

*"This is all part of getting the facts. Understanding the facts will make you communicate better with everyone."*

*If you're really involved, I think the doctors have more respect, they're more likely to listen to you. They feel like you're concerned."*

*You need to set goals for your husband and his life; it's really about what you want to accomplish through therapy. So there are times when I don't think you should be afraid to speak up. Maybe they're the expert—the physical therapist or the speech therapist—but you should speak up and tell them what your goals are. If they're not meeting them, then you should not be afraid to tell them or—if it's not working out— request another therapist. If it's just not working out or you feel something's not right, don't be afraid to ask for another person to work with."*

- Patty H.


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## How Do I Advocate to Employers and Others?

You may need to advocate on behalf of your service member/veteran with TBI to assure access to employment, transportation, or commercial places.

The Americans with Disabilities Act (ADA) requires that employers, public transportation, and commercial businesses not discriminate against people with disabilities. It requires reasonable changes to be made so that the person can work, ride on public transportation, and/or use commercial places.





If you think your service member/veteran with TBI is being discriminated against, speak up. Get to know your family member's rights under the ADA and how to advocate on his or her behalf by going to <http://www.ada.gov>.

## How Can I Advocate to the Broader Community?

After you have some practice as a caregiver to a person with TBI, you will begin to know what life is like with TBI and what families affected by TBI need.

Those who have not lived your experiences may have no idea what you have gone through. You can educate others and raise public awareness of the impact of TBI on individuals and families... through advocacy.

When you are ready, you can educate others by sharing your experiences with them. You may find it helpful to work with others in the local chapter of the Brain Injury Association of America (see Appendix) or the Wounded Warrior Project (see Appendix) on more organized efforts to raise awareness of TBI.

Working with others will bring you into contact with other people who have also walked in your shoes. It may help bring meaning and a greater purpose to your family's experience.

## How Can I Advocate to Policy Makers?

The time may come when you want to broaden your advocacy skills to change the policies or laws of local, state, or federal government.

Systems advocacy uses many of the same skills that you have been learning. Join with others to help pass important laws. Veterans and military service groups as well as TBI-related groups may be interested in advocating for change.

**Laws such as the Americans with Disabilities Act and the Family and Medical Leave Act were passed due to the advocacy of people just like you.**

You may find the idea of being an advocate hard or scary. Most family caregivers grow more at ease over time as they practice these skills.

You will have moments of triumph and moments of setbacks. But if you keep at it, you will find that your own confidence and skills will grow and change you as a person. And, you will have made a difference in the world.

The Brain Injury Resource Center (<http://www.headinjury.com/advocacy.htm>) and the Brain Injury Association of America (<http://www.biausa.org/media.htm>) have tool kits, fact sheets, and other materials to help you develop your TBI advocacy skills.

There are groups who can help you speak up for your family member. Veterans service organizations and military service organizations can also advocate on your behalf. See [www.disabilityinfo.gov](http://www.disabilityinfo.gov) for more information.

*"I wish I didn't have to work a real J-O-B full time so that I could really jump up and down and do a lot more than I do. But I'm starting to learn the ins and outs politically, and I've started really pulling on my Congressman's ears and my Senators' ears. I promised my son, and I promised the two families of his best friends, that, until I can't do it anymore, I wouldn't stop advocating on their behalf, because it's going to be around forever, and I'm not going to be here forever to take care of my son. Somebody is going to have to, and it should be our nation and our system. These kids were not drafted, they volunteered to serve. They deployed, some of them volunteering to go back over and over again, and it's the least we can do. We are not doing enough, we are not doing enough.*

*This is my niche. This is where it works. This is where all the pieces fit together, and this is where I can do the most. People say, 'Well, Adam has been out for a year and a half now, and there's no reason for you to have to devote so much time to all this.' I just think to myself, 'You just don't get it. It's not a matter of having to. It's what needs to be done, and I can do it, and I can do it well. I'm going to do it.'"*

- Cyd D.







## **What Are the Basics of Speaking Up for My Family Member?**

### **1. Identify Yourself**

State your name and identify yourself as a caregiver/constituent.

### **2. Be Specific**

Clearly describe the issue and state your goals. If you are advocating on behalf of proposed legislation, include the name and number of the relevant bill.

### **3. Make it Personal**

The best thing you can do as an advocate is to give the issue your individual voice. Use personal examples and speak in your own words.

### **4. Be Confident**

You may also know more about the issue than the person to whom you are advocating. That is why it is a good idea to offer yourself as a source of information.

### **5. Be Polite**

Always work on the basis that your opponents are open to reason and discussion. If you are rude, your message will not be received.

### **6. Be Brief**

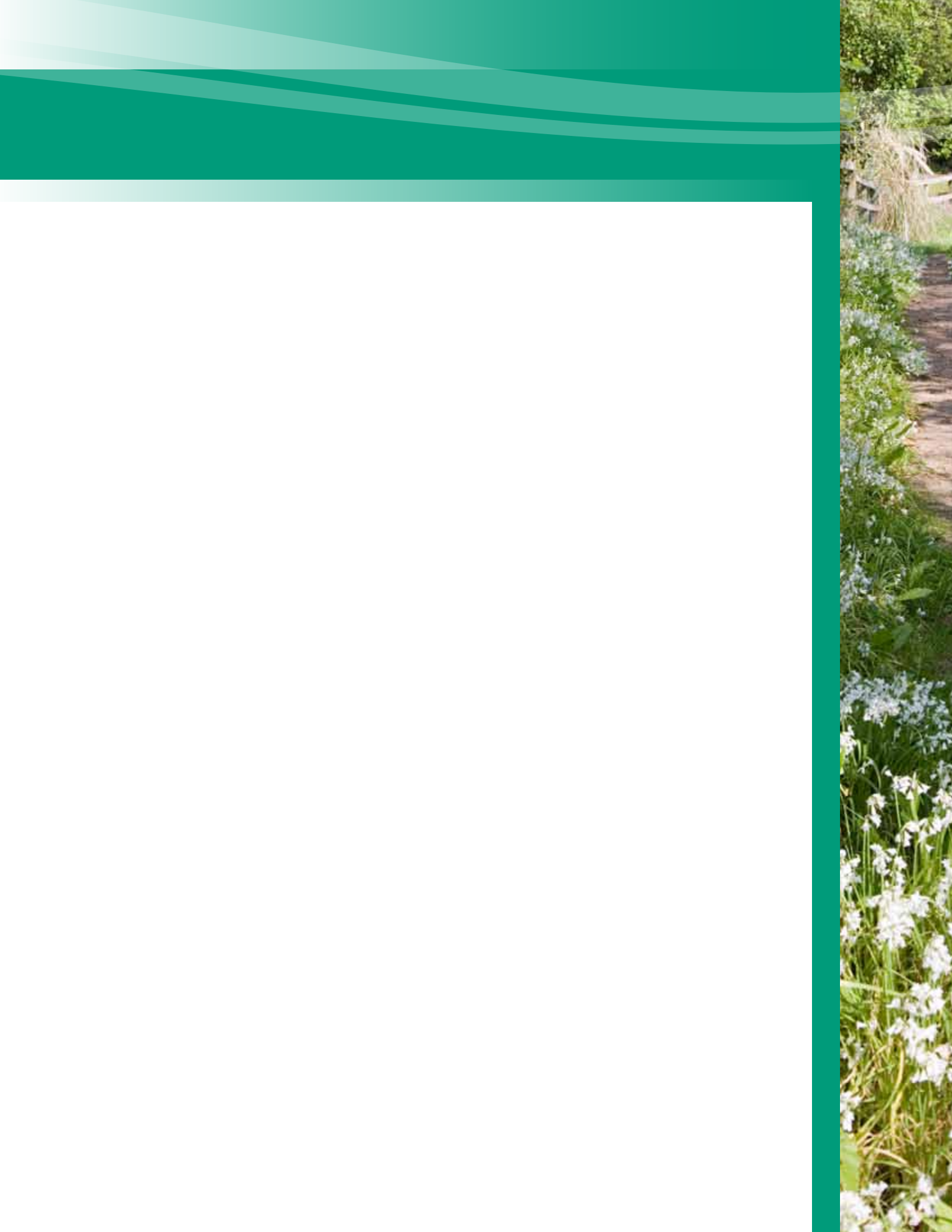
Communication that focuses strongly on one argument is the most effective. Keep it to one issue. Limit written documents to one page.

### **7. Be Timely**

Your message is more likely to be considered if it is immediately relevant.

### **8. Be Factual**

Use facts and statistics. Make sure the information you provide is accurate.





## Taking Care of Yourself

### Whose Care Comes First?

Caregiving requires you to take on new roles. You will need to learn new skills to help your family member with TBI.

Keep in mind, all these new demands happen at the same time that you and your family are coming to terms with the impact of TBI on your loved one.

You want to give the best possible care and support for your family member's recovery. You may find yourself spending all your time and energy dealing with your family member's needs. This may leave you feeling drained.

You may be tempted to put your own needs on hold. It's not wise to do this. You won't be able to give the best care or cope with your new tasks.

*The very best thing you can do to take care of your family member with TBI and others in your family who depend on you is to take care of yourself.*

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*"I went and saw a psychologist and that was probably one of the best things I did. It was for two days a week, an hour each session, and she was just... a neutral person. I could come in and say all this stuff was going on, and she would actually help me make decisions as to where to go next or what things to do for Pat. She could stand back, look at everything, and help me make sense of it. That was a huge help for me. It was an hour that was just about me and we could talk about what was going on. She could put things in perspective for me when I couldn't. I probably saw her for six months.*

*We got involved in the community. We found a church, and that was a great blessing because the people in the church really supported us while we were there. They invited us to do things in the community away from the hospital.*

*I also joined the women's soccer team. The hospital provided a place for Pat to be on Tuesday night, and I could get away and play.*

*Later on, I needed a reason to go to the gym, so we put together a team to run the Army 10-miler for Pat. I had a reason to go to the gym because I needed to train. It's something for me--I did it last year, I ran 10 miles! We are doing it again this year."*

- Patty H.





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*"I know you can only tell others so many times about taking a break and getting away from the hospital. But I wish I would have taken more time at the front end of the whole injury because as Mike has improved, he needs me more and more, and I want to be with him more and more. I have less and less time to go about and do my own stuff, whereas when he was lying in the hospital all day with his eyes closed, I should have gone and relaxed and researched and taken care of things.*

*I know you can only tell people that so many times, but it really takes them learning that in order to take care of themselves. It is a big thing for caregivers to realize that they don't have to feel guilty about stepping away."*

- Meredith H.


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## How Can I Stay Emotionally Healthy?

You may move through a series of stages as you come to terms with the changes in your family member. In the first couple of months, for example, you may be feeling happy that your service member/veteran is alive and hopeful that he or she will recover fully and quickly. As time goes by, progress may slow and you may feel anxious and scared. Sometimes you think that a full recovery might happen faster, if only he or she would work harder at it. As recovery progresses, you may find yourself feeling discouraged and depressed or even guilty. You just don't know how to help your family member get better.

Feelings of depression may progress into feelings of despair and a sense of being trapped, if recovery slows down over time. If your service member/veteran has sustained a severe TBI and recovery is difficult, you may find yourself experiencing a period of grief and deep mourning. Eventually—and this may take up to two years or longer—you may find yourself stepping back from the pain, accepting what is, and finding peace in your family's situation.

You may not go through these stages exactly like this. Knowing what many caregivers and family members go through as they adjust to life after TBI may help you know that your reactions are "normal."



Although your reactions are normal, there can be harmful effects if you focus all your attention on your service member/veteran:

- You may experience **caregiver burnout**.
- If you do not take care of yourself—emotionally and physically—you may end up being harmful to yourself.
- You may feel listless, isolated, or bottled up. Those who are burned out may try to use alcohol to cope. You may have poor hygiene or have emotional outbursts. These are signs of burnout and compassion fatigue. **Compassion fatigue** is an outcome of chronic, unrelieved stress.

*Burnout is feeling hopelessness about your situation.*

*Compassion fatigue is the stress resulting from helping or wanting to help a suffering person.*

You can take the Caregiver Assessment at the end of this chapter to see whether this is something happening to you.

If you do find yourself suffering from caregiver burnout or compassion fatigue, take heart in the knowledge that you are a deeply caring person.

Here is a list of what you can do:

- Find a friend or family member to talk to about your feelings or join a support group with other families affected by TBI. Talking with someone can relieve stress and reduce anxiety because you will learn you are not alone.
- State affiliates of the Brain Injury Association of America (see Resources in the Appendix) can help you find a support group.
- If stress, sadness, or anxiety begins to feel out of control, seek professional help from a counselor, therapist, religious/spiritual leader, or social worker.
- See Module 4 for information about counseling help for military/veteran family members.
- The table on page 22 describes many of the common issues that caregivers face. Also, the table offers ideas for steps you can take to cope.

*Take steps to take care of yourself*

## How Can I Stay Physically Healthy?

Healthy behaviors can keep you well. They can help you cope with the stress of caregiving. This section contains some healthy lifestyle tips. The more you take care of yourself, the better you will feel.





*"I suppose the most challenging thing is adjusting from what was to what is. That transition was really difficult for me because of lack of information. You start to feel like, oh my gosh, I'm going to have to take care of this person and I'm going to be cut off from the world for the rest of my life because I'll just have to be at home with this person 24/7.*

*That was really tough, and I wish I would have known before how many options are out there and that you're not going to be stuck. There are ways to be able to get away and to feel that freedom, and that was a really big challenge for me. It scared me a lot. Being a 25-year-old young woman, married for four years, I just really didn't think that's what I had in my future.*

*For me personally, I really had to come to terms with the fact that the Mike that I married had changed and that I had a new Mike. There were a lot of things that were very similar to the old Mike, and a lot of things that reminded me of the old Mike, but this is a new person and I have to have new expectations and new goals, and everything had to shift and change. I think once that all happened for me, I mean, I'm really happy. I love Mike and I love that he's still here with me and that we're able to do things, and part of that has to do with our relationship before. What helped was just coming to terms with the fact that things had definitely changed but not always for the worst. I need to be open to the fact that it is a change."*

- Meredith H.

## Sleep

*Most adults need 7 to 8 hours of sleep per night.*

If you don't get enough sleep, you are likely to be tired and irritable during the day. You also may find it hard to concentrate. Studies show that people who do not get enough sleep are less productive, tend to overeat, and are even more likely to get in accidents.

Try these tips for getting a comfortable night's sleep:

- **Establish a routine for when you go to bed and when you get up every day.** This can reinforce your body's sleep-wake cycle.

*"Just stay strong and pace yourself, and definitely seek help. Seek a support group and have that network for yourself, because you're going to need it. You're in it for the long haul. You're not going to give them a new brain and everything is going to be better and they're going to learn everything again. It's not like an amputation. There's no prosthetic, and that's the hard thing to swallow."*

- Sandy M.



- **Establish a relaxing bedtime routine.** Take a bath, read a book, or find another activity that helps you shift from your busy daytime life to restful sleep.
- **Go to bed when you're tired and turn out the lights.** If you can't fall asleep, get up and do something else until you're tired.
- **Do not rely on sleeping pills.** Check with your doctor before taking any sleep medications, as they can interact with other medications or a medical condition. You may have an underlying sleep disorder that requires treatment.
- **Don't exercise close to bedtime.** It may make it harder to fall asleep.
- **If you are having trouble sleeping, use the tips above to ease your concerns.**
- **Avoid too much alcohol and caffeine.** Too much of either usually reduces the quality of sleep.
- **Have someone stay over to take over the care duties during the night.**

### Eat a Healthy Diet

A healthy diet is one that is low in fat, high in fiber from whole grains, fruits, and vegetables, and includes lean cuts of meat, poultry, eggs and other protein sources. A healthy diet also helps you to maintain a healthy weight.

It can be tempting to overeat. Do not use food as a comfort when you are stressed and sad. You may gain unwanted weight.

Use low-calorie versions of comfort foods, e.g., sugar-free hot chocolate, or find other ways to comfort yourself, such as a hot bath or a good book.

*It's hard to sleep when you're worried about your family member's medical condition, unpaid bills, or legal issues.*

*For information on how to eat healthfully, consult the Dietary Guidelines for Americans and the Food Guide Pyramid at <http://www.mypyramid.gov/guidelines/index.html>.*



## Coping with Caregiver Challenges

Challenge	Symptoms	How to Cope
<p><b>Stress</b></p> <p>Stress is the mental and physical reaction to events that upset our balance in life.</p> <p>Chronic stress that doesn't go away can lead to serious health problems over time.</p>	<ul style="list-style-type: none"> <li>• Headaches</li> <li>• Neck and shoulders tighten</li> <li>• Fatigue</li> <li>• Trouble sleeping</li> <li>• Weight change</li> <li>• Stomach upsets</li> <li>• Increased use of alcohol, drugs, tobacco</li> <li>• Fear and worry</li> <li>• Mood swings</li> <li>• Crying spells</li> <li>• Irritability</li> <li>• Depression</li> <li>• Forgetfulness</li> <li>• Poor concentration</li> <li>• Low productivity</li> <li>• Negative attitude</li> <li>• Confusion</li> <li>• Weariness</li> <li>• Boredom</li> <li>• Feelings of isolation</li> <li>• High blood pressure</li> </ul>	<ul style="list-style-type: none"> <li>• Deep breathing and other relaxation methods</li> <li>• Exercise</li> <li>• Time management</li> <li>• Meditation</li> <li>• Respite care to get breaks</li> <li>• Take help from friends and family when it is offered.</li> <li>• Humor</li> <li>• Keep some things from your previous life that are important to you.</li> <li>• Reward yourself.</li> <li>• Stay in touch with friends.</li> <li>• Set limits.</li> <li>• Join a support group.</li> <li>• Contact a therapist.</li> <li>• Read a book.</li> <li>• Listen to music that lightens your mood.</li> </ul>
<p><b>Sadness, Depression</b></p> <p>Sadness and grieving are normal responses to the loss of life as you once knew it. Sadness and grieving can lead to depression.</p> <p>Symptoms of depression are a combination of symptoms that interfere with a person's ability to work, sleep, study, eat, and enjoy once pleasurable activities.</p> <p>Major depression is disabling and prevents a person from living normally.</p>	<ul style="list-style-type: none"> <li>• Feeling blue</li> <li>• Feeling sad</li> <li>• Withdrawing</li> <li>• Irritability</li> <li>• Constant sad, anxious, or "empty" feelings</li> <li>• Feelings of hopelessness and/or gloom</li> <li>• Feelings of guilt, being worthless, and/or helpless</li> <li>• Bad temper, restless</li> <li>• Loss of interest in activities or hobbies once enjoyable, including sex</li> <li>• Tired and decreased energy</li> <li>• Trouble concentrating</li> <li>• Trouble remembering details and making decisions</li> <li>• Can't sleep, early-morning wakefulness, or too much sleeping</li> </ul>	<ul style="list-style-type: none"> <li>• Talk over your feelings with others, e.g., in a support group.</li> <li>• Keep a journal to explore your feelings. Give yourself a break, by asking for help in caregiving.</li> <li>• Try to rest both your body and your mind.</li> <li>• Find someone who can listen without giving advice or making comments.</li> <li>• Focus on positive relationships in your life – family, friends, and pets.</li> <li>• Know your limits in caregiving. It is okay to seek help from others if caregiving becomes too much for you.</li> <li>• See Chapter 6 for ideas for a back-up plan.</li> </ul>



## Coping with Caregiver Challenges

Challenge	Symptoms	How to Cope
<b>Sadness, Depression</b>	<ul style="list-style-type: none"> <li>• Overeating or appetite loss</li> <li>• Having thoughts of wanting to be dead rather than living in all this pain--"I would rather be dead than deal with all this pain and suffering."</li> <li>• Suicide attempts</li> <li>• Constant aches or pains, headaches, cramps, or stomach problems that do not ease, even with treatment</li> </ul>	<ul style="list-style-type: none"> <li>• See Chapter 7 for organizing help from family and friends (Home Care Team).</li> <li>• If symptoms persist, seek professional help. Counseling and/or medications have proven effective in treating depression.</li> <li>• Seek help immediately from medical care staff if you have thoughts of suicide. Seek counseling and/or medications from a provider.</li> </ul>
<b>Anxiety</b>  Anxiety is excessive worry about life. It is a reaction to stress and can lead to depression.	<ul style="list-style-type: none"> <li>• Ongoing worry and tension</li> <li>• Viewing problems as overwhelming</li> <li>• Restlessness or a feeling of being "edgy"</li> <li>• Bad temper</li> <li>• Muscle tension</li> <li>• Headaches</li> <li>• Sweating</li> <li>• Difficulty concentrating</li> <li>• Nausea</li> <li>• Needing to go to the bathroom often</li> <li>• Being tired</li> <li>• Trouble falling or staying asleep</li> <li>• Trembling</li> <li>• Being easily startled</li> </ul>	<ul style="list-style-type: none"> <li>• Use problem-solving methods (see below).</li> <li>• Talk to a friend or family member.</li> <li>• Exercise.</li> <li>• Eat a balanced diet.</li> <li>• Avoid caffeine.</li> <li>• Write in your journal.</li> <li>• If symptoms persist, seek professional help.</li> <li>• Counseling and/or medications can effectively treat anxiety.</li> </ul>

## Exercise

Exercise can relieve stress, reduce depression, make you feel better about yourself, help you maintain your weight, and give you some time alone.

It doesn't have to be strenuous. A 30-minute walk on most days is usually enough to protect your health. You can break the 30 minutes into shorter 10-minute segments, if that's all the time you have.

If you already have an exercise routine in place, try to stick with it. Doing things that were important to you before the TBI can help you cope. You will be a better caregiver.

*Exercise is one of the single best ways to protect your health.*



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*"I didn't do a very good job of taking care of myself, and it didn't take its toll until about four years later. Now I'm paying the consequences. My blood pressure is high. Physical things are cropping up. During the first year, I didn't take care of myself.*

*I didn't sleep. When I'd go to bed, things would just run through my head. When I finally did go to sleep, I woke up in the morning with reality hitting me in the face, like I can't believe this is my life. You get out of bed and you just put one foot in front of the other."*

- Denise G.

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If you are new to exercise, check with your personal health care provider and start out slowly. Remember to include stretching and strength building in your routine.

There are many exercise videos that you can use at home. You don't need to find the time or money to go to a gym.

### **Tobacco Use**

If you don't use tobacco products, don't start. Find other ways to cope with the stress.

If you use tobacco products, stress may increase your tobacco use. If you use tobacco products, it may be difficult to quit during periods of stress, such as when you are learning to care for someone with TBI.

Your goal right now may be simply to not increase the number of tobacco products you use each day.

Later, you may want to start cutting down on the number of tobacco products and then quit altogether.

The nicotine in tobacco is addictive. Most smokers find it takes several attempts to quit before they are successful. Ask your doctor about medications or programs that can help you quit.

### **Alcohol and Other Drugs**

When life is stressful, you may find it difficult to solve problems, make decisions, and take care of yourself.

*Using any form of tobacco damages your health.*

*Be realistic.*

Some people turn to alcohol or other drugs to help them relax. Alcohol tends to make problems worse.

Using alcohol or drugs to make you feel better in the short term can be dangerous. You can become dependent on these substances. This will interfere with your responsibilities to your family.

If you drink, do so in moderation (i.e., one drink per day for women, two drinks per day for men). Find other ways to relieve stress and to reward yourself for doing a hard job well.

### Routine Medical Care

Remember, you can't take care of someone else well unless you are strong and healthy.

This includes getting routine medical and dental care, such as preventive screenings (e.g., mammograms, blood pressure checks) and regular attention to medical problems that you may have.

It's okay to have your family member with TBI sit in the waiting room while you see the doctor, dentist, or other provider if he or she is able, or make plans for care if he or she cannot be left alone.

If you become sick, worn down, or burned out, you will not be able to provide good care to your family member.

Take care of yourself first. It's not being selfish. It is being realistic and loving to you, your loved one, and other family members.

*You can't take care of yourself or someone else if you're drunk or high.*

*Caregivers often overlook their own health as they struggle to cope with the medical needs of their loved ones.*

*"No, I didn't take care of myself, and I still haven't really, two years later. Now I'm getting to the point where I've realized that I've neglected myself, just the routine things, like doctor appointments, dental appointments, and physicals for myself. I've ended up with a lot of stomach problems as a result. Now I'm trying to play catch-up because I didn't really take care of myself the last couple of years. That's been kind of a downer, I guess you could say."*

- Aimee W.





## What Are Strategies for Self-Care?

### Problem Solving

Learning how to be a good problem solver can help you cope with stress and reduce anxiety. Here are some simple problem-solving steps:


- Identify the problem. If the problem has many parts, break it down into one problem at a time.
- Brainstorm solutions. Think of as many possibilities as you can.
- Assess options. Consider the pros and cons of each possibility.
- Choose a solution that seems to fit best for you.
- Try the solution out.
- If it didn't work, try another solution until you find the one that works.

### Stress Busters

*Paying attention to your emotional and physical health is the most important thing you can do to help your family member with TBI.*

- Practice deep breathing. Take a deep breath, hold it for a few seconds, and then let it out. Continue to breathe deeply until you feel yourself calm down.
- Relax your muscles. Lying down, begin by tensing your toes, then relaxing them. Then tense your ankles and relax. Continue up your body to your forehead, tensing and relaxing each set of muscles. Then lie quietly for a few minutes, letting your body melt into the floor.
- Try meditation. Select a quiet spot in the house and a time when you can be quiet for 15 minutes. Sit down and rest your hands in your lap. Close your eyes. Clear your mind. Breathe in deeply, then let your breath out while you say a word such as "one." Repeat continuously. Try to clear all thoughts from your mind as you do this—it takes practice, but you'll find yourself able to do so for longer and longer periods of time.
- Manage your time effectively. Plan ahead so that you have enough time to arrive at appointments on time. Plan your day or week sensibly, so that you are not trying to get too much done in too little time.
- Find time to exercise. Exercise helps your brain release **endorphins**. It also gives you some alone time.
- Try Tai Chi or yoga. Many people find these activities helpful to relieve stress.
- Find ways to relax and take your mind off your daily routine: Read a book, watch your favorite movie/TV show, or spend time with a friend.

*Endorphins are natural substances in your body that reduce stress and make you feel better.*



The worksheet below helps you to evaluate your stress level.

You can ask health care providers to teach you stress reduction strategies and to provide you with relaxation tapes.

## The 13-Item Stress Test

- |          |       |  |
|----------|-------|--|
| 1. True  | False | I have a lot to do.                                    |
| 2. True  | False | I have more to do than I can handle.                   |
| 3. True  | False | I'm not being productive.                              |
| 4. True  | False | I'm trying really hard, but getting nothing done.      |
| 5. True  | False | I'm feeling unhealthy.                                 |
| 6. True  | False | I can't afford to take breaks or time off.             |
| 7. True  | False | I'm pushing myself too hard.                           |
| 8. True  | False | I don't sleep very well.                               |
| 9. True  | False | Too many people are telling me what to do.             |
| 10. True | False | I am not treating people the way I want to be treated. |
| 11. True | False | I feel totally exhausted.                              |
| 12. True | False | Nobody is happy with what I do.                        |
| 13. True | False | I can't stand living like this.                        |

Scoring: The more True responses you circle, the greater the pressure you're feeling. Refer to the Stress Buster ideas on page 26 for suggestions to decrease stress.

## Caregiver Self-Assessment Questionnaire

How are you?

American Medical Association  
Physicians dedicated to the health of America



Caregivers are often so concerned with caring for their relative's needs that they lose sight of their own wellbeing. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have...

- |  |   |
|--|---|
| 1. Had trouble keeping my mind on what I was doing ..... <input type="checkbox"/> Yes <input type="checkbox"/> No                          | 15. Been satisfied with the support my family has given me ..... <input type="checkbox"/> Yes <input type="checkbox"/> No   |
| 2. Felt that I couldn't leave my relative alone ..... <input type="checkbox"/> Yes <input type="checkbox"/> No                             | 16. Found my relative's living situation to be inconvenient or a barrier to care ..... <input type="checkbox"/> Yes <input type="checkbox"/> No                   |
| 3. Had difficulty making decisions ..... <input type="checkbox"/> Yes <input type="checkbox"/> No  | 17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress. _____                        |
| 4. Felt completely overwhelmed ..... <input type="checkbox"/> Yes <input type="checkbox"/> No  | 18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year. _____ |
| 5. Felt useful and needed ..... <input type="checkbox"/> Yes <input type="checkbox"/> No   | Comments:<br>(Please feel free to comment or provide feedback)  |
| 6. Felt lonely ..... <input type="checkbox"/> Yes <input type="checkbox"/> No  | _____   |
| 7. Been upset that my relative has changed so much from his/her former self ..... <input type="checkbox"/> Yes <input type="checkbox"/> No | _____   |
| 8. Felt a loss of privacy and/or personal time ..... <input type="checkbox"/> Yes <input type="checkbox"/> No                              | _____   |
| 9. Been edgy or irritable ..... <input type="checkbox"/> Yes <input type="checkbox"/> No   | _____   |
| 10. Had sleep disturbed because of caring for my relative ..... <input type="checkbox"/> Yes <input type="checkbox"/> No                   | _____   |
| 11. Had a crying spell(s) ..... <input type="checkbox"/> Yes <input type="checkbox"/> No   | _____   |
| 12. Felt strained between work and family responsibilities ..... <input type="checkbox"/> Yes <input type="checkbox"/> No                  | _____   |
| 13. Had back pain ..... <input type="checkbox"/> Yes <input type="checkbox"/> No   | _____   |
| 14. Felt ill (headaches, stomach problems or common cold) ..... <input type="checkbox"/> Yes <input type="checkbox"/> No                   | _____   |



To Determine the Score:

- 1.Reverse score questions 5 and 15. (For example, a “No” response should be counted as “Yes” and a “Yes” response should be counted as “No”)
- 2.Total the number of “yes” responses.

### To Interpret the Score:

Chances are that you are experiencing a high degree of distress:

- If you answered “Yes” to either or both Questions 4 and 11; or
- If your total “Yes” score = 10 or more; or
- If your score on Question 17 is 6 or higher; or
- If your score on Question 18 is 6 or higher.

### Next steps:

- Consider seeing a doctor for a check-up for yourself.
- Consider having some relief from caregiving. (Discuss with the doctor or a social worker the resources available in your community.)
- Consider joining a support group

## Valuable Resources for Caregivers:

Eldercare Locator:  
(a national directory of  
community services)  
1-800- 677-1116  
[www.aoa.gov/elderpage/  
locator.html](http://www.aoa.gov/elderpage/locator.html)

Family Caregiver Alliance  
1-415- 434-3388  
[www.caregiver.org](http://www.caregiver.org)

Medicaid Hotline  
Baltimore, MD  
1-800-638-6833

National Alliance for  
Caregiving  
1-301-718-8444  
[www.caregiving.org](http://www.caregiving.org)

National Family  
Caregivers Association  
1-800 896-3650  
[www.nfcacares.org](http://www.nfcacares.org)

National Information  
Center for Children and  
Youth with Disabilities  
1-800-695-0285  
[www.nichcy.org](http://www.nichcy.org)

### Local Resources and Contacts:

[illegible]

# Journal

*The questions below can help you reflect on your experience as a caregiver. You can write your thoughts here, copy this page and add it to your journal if you keep one, or reflect on these questions in your journal.*

*What are the main sources of stress in my life? How do I handle it? How could I handle it better?*

*Other ideas for emotional self-care that I will try:*

*Ideas for taking care of myself physically that I plan to do:*



## Helping Your Children Cope with TBI

Having a parent with TBI can be frightening for a child who looks to his or her parent to provide strength and safety.

The parent with TBI may no longer act the same as he or she did before the injury. Your family member/parent with TBI may be angry, depressed, or uncertain.

As a result, the special parent-child bond that existed previously has changed.

Children may be confused and upset about what is going on. This could be due to worry about a parent's condition or concerns about changes in their parents' relationship. It could also be due to financial strains, or simply adjusting to the new "normal."

It is important to recognize that your children are grieving, just as you are. They may withdraw from social activities with peers, have mood swings, become withdrawn or disruptive, do poorly in school, and show other behavioral problems.

Children also need time and space to be kids. Communicate with your child that he or she is not to blame for the TBI.

Some children may need to take on some caregiving tasks for the parent or for younger children in the family. Children who care for parents or other relatives experience considerable conflict over the reversal of roles between parent and child.

Make sure any tasks that your child takes on—household chores, for example—are suitable for his or her age. Strive as much as possible to

*Many children feel as if they have lost both parents: one to TBI and the other to caregiving.*

*Remind your children that you are the caregiver and that they can rely on you to be their parent.*

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*"Thankfully, they're pretty adaptable, but still they're kids, and that's why we've had to seek counseling. My son is dealing with secondary post-traumatic stress disorder. He's very terrified that every time my husband goes in the hospital, he's not going to come home. So we deal with that. With my daughter, we're kind of dealing with the teenage issues. Plus she's pretty angry at my husband.*

*He's not who he used to be. You know, I think the key is talking, keeping the lines of communication open, letting your kids express to you if they're mad, angry, whatever it is. It's okay. Emotions are okay. Do not hold it in because that's going to make it worse in the long term."*

- Anonymous

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*Children need  
time to grieve.*

find other adults to help you, rather than relying on your children to play a major caregiving role.

You can help your children by explaining TBI in a way that they can understand (see below). Ask a health care provider to talk with your children.

Build new family routines, and keep an eye out for signs that your child is not coping well.

The table on page 34 offers some ways to explain TBI to children of different ages. If your child appears to be depressed for a long time or he or she begins taking on risky behaviors, seek professional help.



*"When Tim was starting to read and do word finding, those games were fun activities for the kids to do with him. They took part in his recovery, and I think that involvement was probably the key factor that kept the children from getting resentful, from being isolated. The kids have told me since then that they had wanted to know about things sooner. They thought that we kept a lot of things from them.*


*I still think that there are some things kids at that age don't really need to know and they learned things along the way that they were ready for. But they did want to know. They're very intuitive. Sharing age-appropriate information meant that they still had a little control in their lives, too. They could then process why Mommy and Daddy had to be away and not go to the dark side of their imagination thinking their worlds were falling apart and not have a clue as to why. I think not discussing the issues is probably the worst thing you can do for your children. They don't like being left in the dark."*

- Shannon M.

## How Can I Tell My Child about TBI?

It is difficult to explain TBI to a child. Yet it is vital to tell your child what is going on. Some adults try to protect children from the truth because they think they are too young to understand.

Children of almost any age are aware that something is wrong and they want to know what is happening.



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*"You know, it's still a daily thing. TBI is definitely a hard thing to grasp. I think the hardest thing, especially for our teenage son, because maybe he is older, is that his Dad is 37 on the outside, but on the inside he's younger. Our son is going to continue to get older and get more mature and grow up, and his Dad is kind of where he's going to be.*

*I just think a lot of communication is the key. Ask them: Do you have questions? What are you struggling with today? What don't you understand? We also go to therapy. I stressed to our son that this isn't going to go away. This is a lifelong disability. We have to learn to deal with it and cope with it, and you can't do it on your own. You cannot do it on your own.*

*Getting plugged in to support groups that are geared for TBI, seeking out counselors that know TBI and can give you strategies on how to deal with situations, those things are important. That's what it's about for us right now. It's about getting the mental help and the feedback that we need and realizing that, really, we're not alone."*

- Anonymous

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Communicate in an age-appropriate way what has happened to your family member with TBI. Protecting your children by withholding information may backfire. Children have active imaginations that may create a scenario worse than reality.

How you tell your child about TBI depends on the age of the child. The table on the next page offers strategies that you can use, depending on the age of your child.

## What Are Specific Ways to Explain TBI to a Child?

Here are some suggestions for how to explain TBI to a child:

- The brain is similar to the command station of a space ship. If a meteorite hit the command station, the crew would not be able to control what the space ship does. If the brain is hurt, it may send out the wrong signals to the body or no signals at all. A person with TBI may have a hard time walking, talking, hearing, or seeing.

## How Can I Communicate with My Child about TBI?

Age and Stage of Development	Communication Techniques for Parents
<b>Age 2-3</b> Can differentiate expressions of anger, sorrow, and joy	<ul style="list-style-type: none"> <li>• Communicate using simple words.</li> <li>• Use picture books.</li> <li>• Create simple books with pictures of family members and simple objects that the child understands (hospital, doctor, bed, rest).</li> <li>• Offer dolls to play with so they can recreate what is happening at home or at the doctor's office.</li> </ul>
<b>Age 4-5</b> More self-secure, can play well with others, tests the rules, 'magical thinking'	<ul style="list-style-type: none"> <li>• Select books with stories that mirror families like yours to help your child relate.</li> <li>• Familiarize your child with pictures of objects and concepts related to medical care and health (hospital, gown, doctors, flowers, bed, coming home from the hospital).</li> <li>• Incorporate play with a child's 'doctor kit' to familiarize your child and symbolize what is happening.</li> </ul>
<b>Age 6-7</b> Capable of following rules, enjoys having responsibility Uncertain of the relationship between cause and effect; parent is the primary source of self-esteem	<ul style="list-style-type: none"> <li>• Use interactive communication—reading books and creating stories with your child.</li> <li>• Help your child create his/her own "this is our family" album and talk about the photographs and memorabilia.</li> <li>• Watch movies with story lines similar to what your family is experiencing.</li> </ul>
<b>Age 8-11</b> Has a better understanding of logic and cause/effect, less centered on self, able to understand others' feelings, can empathize	<ul style="list-style-type: none"> <li>• Listen to your child's thoughts and opinions.</li> <li>• Ask questions that go beyond yes and no.</li> <li>• Depending on your child's level of development and understanding, speak with direct, reality-based explanations that include facts.</li> <li>• Include the sequence of events involved, and what to expect.</li> </ul>



Age and Stage of Development	Communication Techniques for Parents
<p><b>Age 12-17</b></p> <p>Experience puberty and physiological changes, seek freedom and independence, acceptance by peers is extremely important, develop more intimate relationships, more thoughtful and caring</p>	<ul style="list-style-type: none"> <li>• Speak honestly and realistically.</li> <li>• Give facts, what is expected to happen including the diagnosis, prognosis, treatments, and expected outcomes.</li> <li>• Talk with your children, not to them.</li> <li>• Check in and offer time to discuss concerns frequently.</li> <li>• Listen attentively.</li> <li>• Ask questions that can be answered with more than 'yes' or 'no.'</li> <li>• Stay alert for risky behaviors, acting out, or noticeably withdrawn (if this is a new behavior).</li> <li>• If risky behaviors are present, seek professional help.</li> </ul>

- The brain is the computer for the body. When injured, it doesn't boot up properly, runs slower, has less memory, etc.
- A broken bone will usually heal and be as good as new. A brain injury may not heal as completely. Even though the person with the injury may look the same, he or she may still be injured. These injuries might include having a hard time paying attention or remembering what you told him or her. He or she may get tired easily and need to sleep. He or she may say or do things that seem strange or embarrassing. He or she may get angry and shout a lot.
- Many people develop anger as a direct effect of the damage to the brain. In other words, the parts of the brain that normally stop angry flare-ups and feelings have been damaged and do not do their jobs as well. The parent with TBI may be mad because he or she can't do the things he or she used to do. His or her feelings may be hurt because others treat him or her differently than before the injury.
- A cut may take a few days to heal, a broken bone a few weeks. Getting better after a brain injury can take months or even years. Sometimes, the person will not get 100 percent better.
- Brain injury changes people. These changes can be confusing. Try to remember that the changes you see are caused by the brain injury. You can still love and care about the person.

*It can be challenging to put TBI into simple terms that a child can understand.*

*More information can be found on [www.neuro.pmr.vcu.edu](http://www.neuro.pmr.vcu.edu).*

*Listen to your children's concerns.*

## What Are Some Tips for Helping Children Cope?

- Provide information to your children about what to expect before they are reunited with their parent with TBI. For example, explain in advance what they may see in the hospital. Describe how their parent will look, behave, and react before he or she comes home.
- Be flexible. Take your cue from your child about when he or she wants to resume his or her normal routine. Encourage children to stay involved with friends and school activities.
- If your children choose to attend their activities, ask friends or relatives to take them. Ask friends to take over caregiving when you need to go to watch your son or daughter play basketball or appear in the school play.
- Encourage your children to talk about their fears, hopes, and worries. Allow safe and appropriate ways for your children to express their emotions.
- Meet with your children's teachers to explain what has happened and the effects on the family.
- Encourage other family members, friends, or other important adults in your child's life to share time with your child and to act as a sounding board, if needed.
- Your children may say upsetting things to you. Just listening can be the best support for them.
- Re-establish routine for your children. Consistent dinner and bed times may help.
- Encourage your children to talk about what familiar characteristics and behaviors of their parent they are starting to see.
- Be easy on yourself and your children. A certain amount of stress is normal.
- Be careful not to set a timeframe with your children for when recovery will occur. Children want it all to happen quickly, and it is hard to predict recovery after TBI.
- Stay alert for changes in their behavior. Get counseling for your child to help him or her cope with grief, especially if the child appears depressed or is adopting risky behaviors.
- Recognize that some children may pull away for a while. Others may regress to younger behavior, becoming very dependent, demanding constant attention, or exploding in temper tantrums. These behaviors should return to normal over time as the child adjusts.

- Teenagers may be embarrassed about their parent with TBI. Rehearse with them how to respond to comments or questions about how their parent looks, behaves, and speaks.
- Sesame Street Workshop has produced videos to help children in military families understand issues related to military service and to help parents communicate effectively with their children about these issues. One video addresses “Changes” that occur when a parent has been injured. You can find these videos at <http://archive.sesameworkshop.org/tlc>.

At the same time that you are providing factual information about TBI, don’t forget to include reassurance that you are still a family and love one another.

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*“Once we felt that he was doing well enough and could express his needs and I didn’t have to be there for 12 hours a day, we had a discussion. We came to the agreement that I would be with him when the kids are in school, but it would be fine for us not to be there every afternoon afterwards because we wanted the kids to have normalcy. We wanted them to go play at the park and have activities and things in the afternoon. So that really took a load off.”*

- Anna E.



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## How Can I Build Stronger Family Ties?

Set time aside each week for your family to spend some fun time together, and move the family focus away from TBI. Try these ideas with your family:

- Have a family meeting. Explain that you plan to hold a family time every week, and ask for ideas for when and what to do (if family members are old enough to participate). Family members could take turns choosing activities.
- Turn off the video, cell phone, e-mail, etc. during family time. Your goal is to interact with and enjoy each other.

*You may not be able to preserve all of your previous family routines, but you can create new ones.*



- Try activities that everyone in the family can enjoy. This might include doing things like playing board games, taking a walk or run, or baking cookies. Find activities where everyone in the family can play a role.
- In addition to family time, schedule some individual time with each family member. Children need to have time alone with their parent(s). This helps them feel heard and appreciated. Plan an activity with each child—a shopping trip, movies, story time—and schedule it in on a regular basis.
- To build closer family ties, encourage the children to play simple games with their injured parent. Such games may also help the injured parent practice skills to help in recovery.
- Think about your family rituals and keep them on the schedule. If you plan elaborate holiday decorations, you may need to cut back this year but you can still celebrate more simply.



*“When my husband was first diagnosed with TBI, he realized he couldn’t do math anymore. So we had to work on math skills. He and the children worked on doing simple math again and learning algebra. Working out math problems helped us come together again as a family. Doing things together brings you close. Even going to all the appointments together helped us bond. It is a trying time, but it does help bring you back together. We are such a close family now.”*

- Lynn C-S.

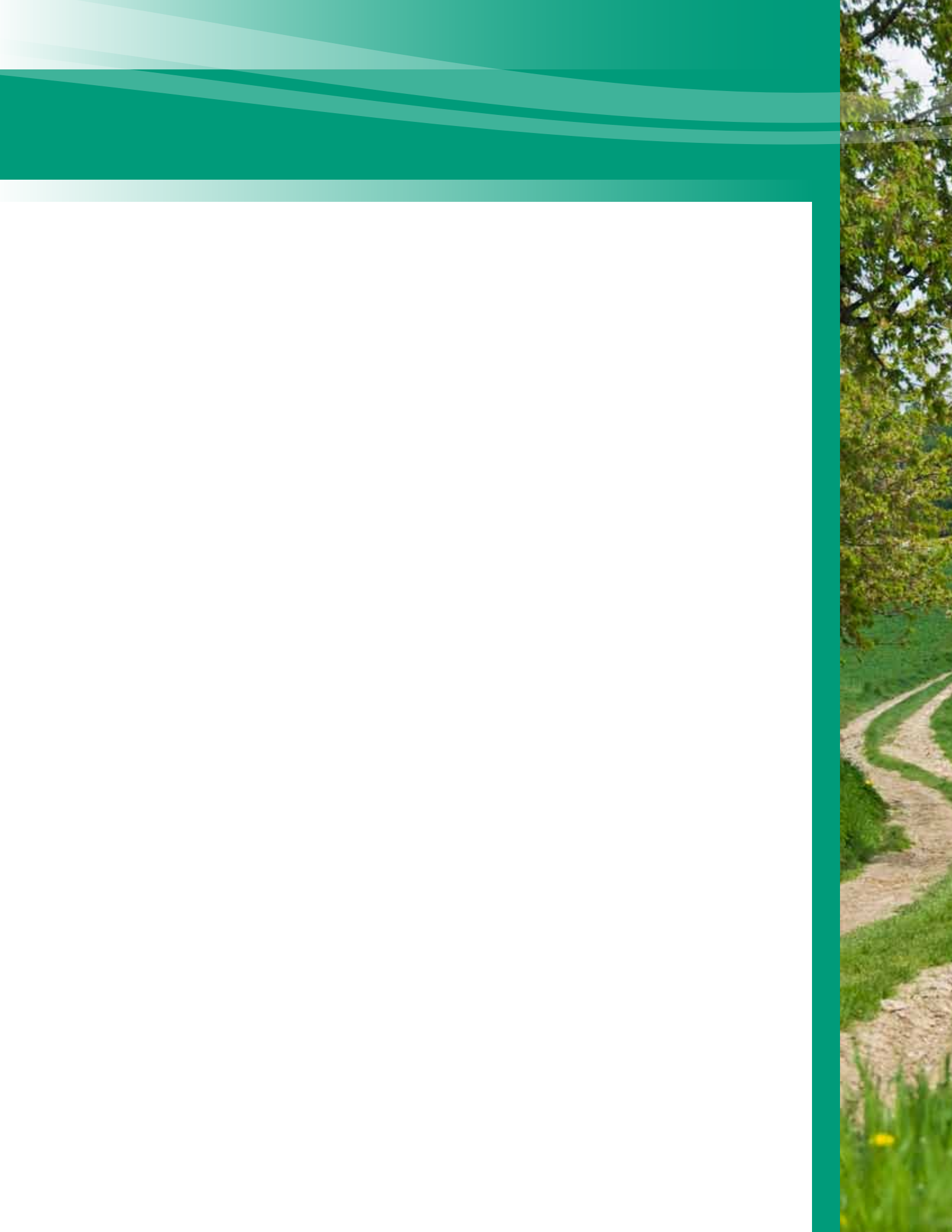


## Journal

*The questions below can help you reflect on your experience as a caregiver. You can write your thoughts here, copy this page and add it to your journal if you keep one, or reflect on these questions in your journal.*

*What questions have your children asked? How are they adjusting to the changes in the family?*

*What new routines do you think your family would enjoy that would help your family adjust to the new normal?*





## Addressing Family Needs

Everyone in the family is affected by TBI. As the primary caregiver, your role within the family has changed. The role of your family member with TBI may also have changed.

Role changes can be emotionally demanding.

Other challenges include learning how to balance work, family, and your own needs, in addition to caring for someone else. Changes in finances, social life, and relationships also add stress to the family.

Conflict among family members regarding the care and treatment of the injured family member may also occur.

Addressing family needs means paying attention to family members' emotional needs and addressing them.

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*"It hasn't been done without a lot of crying. The dynamic on the family is awful. It will either make you or break you."*

- Nellie B.

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### How Can I Build on My Family's Strengths?

You can learn to cope with the stress of TBI by finding and building on your family's strengths. No family is perfect.

As you read this section, think about your family's strengths. Then think about areas that you would like to be stronger. Discuss these with family members and choose one area that you can work on together.

Family strengths include:

- **Caring and Appreciation**
- **Commitment:** One way to build commitment is to create and maintain family traditions.
- **Communication:** It's important to keep lines of communication open. Active listening is important. When the other person is telling you how he/she feels, try re-stating what he/she just said to see if you understand his/her position correctly.

*All families have strengths and weaknesses.*

- **Community and Family Ties:** Keeping close ties with relatives, neighbors, and the larger community can provide useful sources of strength and help in trying times.
- **Working Together:** Sharing tasks and decision making will help your home run smoothly. When important decisions need to be made, all family members should share their points of view.
- **Flexibility and Openness to Change:** A TBI in the family means that everyone's roles and responsibilities will shift. Learning to manage change can be a challenge, but it can be done.

Use "I" statements to share your feelings, rather than "You" statements. For example, if you're upset because your brother didn't show up to drive you to the hospital on time, you might say: "**I** feel upset when you are late to pick me up. **I** am anxious to get to this important medical appointment on time so that I have the doctor's full attention" instead of, "**You** are always late."

The former states your feelings; no one can argue about your own feelings. The latter attacks the other person, making him or her feel defensive and more inclined to argue with you.

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*"It's just frustrating to not have the same kind of relationship, to have to be more of a caretaker than a partner, or a mother/son or a mother/daughter. You know, people who are injured have all kinds of things going on in their own head, so it's hard for them to relate to you because they're going through their own agony. So the frustration of being that person sometimes is just hard."*

- Anonymous

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## How Can I Preserve My Marriage or Relationship?

TBI can affect the dating or marital relationship, just as it affects other areas of family life.

In addition to the stress that caregiving may bring, the spouses of people with TBI may lose the intimacy with their partner that they once enjoyed.

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*Intimacy is the emotional and physical closeness between partners. It consists of both emotional and physical/sexual intimacy.*

*“Intimacy is something that I think a lot of couples with TBI have trouble with. Some too much, some too little – but certainly changes from pre-injury. In our case, there were periods of more emotional withdrawal, whether from the medications or the injury itself. For me personally, helping other families has filled that emotional void. Focusing on the children and focusing on my husband has filled that emotional void in a different way.*

*Physical touch, I’ve found that massage really helps. When I’m feeling like I’m just out there on my own, sometimes if I go get a massage, then that sort of relieves that physical tension.”*

- Anonymous

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Following a TBI, your service member/veteran may experience effects of the injury that may affect your relationship. Module 2 describes the possible physical, cognitive, emotional, and behavioral effects of TBI. Most of these changes improve over time.

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*There may be changes in sexual interest and activities due to TBI.*

*“You feel very nervous or not so comfortable talking to the doctors about sexuality or what’s happening, especially in the early stages. But it’s a big concern for a wife. It’s a big concern for me, especially because we don’t have any kids yet. So it could mean... who knows... no kids, or it could mean...? It was just a big concern for me.”*

- Anonymous

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People with TBI may lose interest in sex, become impotent, or may not be able to have an orgasm. This is often due to biological changes or the medications that they may be taking. This is a common effect of TBI, so do not hesitate to talk with your provider about this.

Some people with TBI may show their sexual interest in ways that are not socially acceptable. They may misinterpret social or vocal cues and therefore behave inappropriately.

Seek professional counseling, if you need it. All marriages go through ups and downs; there is no stigma in seeking help. Military family advocacy programs and other on-base support programs provide a resource for counseling and help.

See Module 4 for counseling resources available to military families.

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*"I think that one of the hardest things is that with a brain injury, you step into the role of being a caregiver..... I've ended up feeling like mom pretty much and not so much a wife, if that makes sense.*

*That's been hard for me, because another issue that we have is his judgment sometimes, the things he does. I feel like I end up being mom. 'No, you can't go spend all your money at once.' I hate that feeling because he views me in that way now. I don't want to be mom to him. So that's really hard.*

*Sometimes I just wish he would go get more counseling for himself. You know how some of these guys are. It's like a sign of weakness to go talk to somebody about things, especially being in the Army. They don't want to admit something is wrong. I've tried to tell him, I can't handle everything myself. So that's been an issue."*

- Anonymous

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## What are Other Ways TBI May Affect My Family?

Spouses and in-laws may disagree about who is the best caregiver or where care should be provided.

If you are experiencing this kind of family conflict, you may need to advocate on behalf of your loved one with TBI to other members of the family. (See Chapter 2 to learn more about advocacy skills.)

Keep in mind that every family member involved in this type of conflict loves the family member with TBI and wants the best for him or her.

Remember that everyone is under a great deal of stress. Try to talk openly about each person's point of view.

Seek professional guidance if you are unable to resolve the issues yourselves.

Caring for your loved one may make existing family issues worse. If you find you are having difficulty with treatment decision making, you can get advice from a member of the health care team.

*Some families experience conflict over the care and treatment of their family member with TBI.*

## What Can I Do If Caregiving is Just Too Much?

It is helpful to know yourself and your limits. Your back-up plan may include finding temporary or more permanent residential care for your family member with TBI. Discuss quality of life issues with your family and health care professionals. Your choices may include:

- Give others permission to care for your loved one.
- Seek assisted living facilities and board and care homes—for those who have difficulty living alone but do not need daily nursing care.
- Consider nursing homes, also called skilled nursing facilities—for individuals who need 24-hour nursing care and help with daily activities. Skilled nursing care can also be provided at home by nurses you hire.

Check with your case manager(s), VA liaison, and/or military liaison for residential care benefits that may be available to your family member with TBI. Also, see Module 4 for benefits available to military/veteran families.

Many organizations will assist service members/veterans and families in paying for additional costs. Talk with your case manager to help learn more about this.

Learn more about residential facilities from this fact sheet from the Family Caregiver Alliance:

[http://caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1742](http://caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1742).

*If caregiving gets too demanding or other circumstances prevent you from being a caregiver, have a back-up plan in place.*

## Sources of Information About Residential Care

<b>Disabled American Veterans</b>	National Service Officer: <a href="http://www.dav.org">http://www.dav.org</a>
<b>Veterans of Foreign Wars</b>	National Service Officer: <a href="http://www.vfw.org">http://www.vfw.org</a>
<b>Paralyzed Veterans of America</b>	<a href="http://www.pva.org">http://www.pva.org</a>
<b>National Resource Directory</b>	<a href="https://www.nationalresourcedirectory.org">https://www.nationalresourcedirectory.org</a>
<b>Long term Care: Veterans Affairs</b>	<a href="http://www.virec.research.va.gov/DataSourcesCategory/LongTermCare/LTC.htm">http://www.virec.research.va.gov/DataSourcesCategory/LongTermCare/LTC.htm</a>
<b>Residential Care</b>	<a href="http://www.dvbic.org">www.dvbic.org</a> : Laurel Highlands NeuroCare, Pennsylvania and Lakeview NeuroCare, Richmond, VA
<b>Vocational Rehabilitation and Employment Program: Veterans Affairs</b>	<a href="http://www.vba.va.gov/bln/vre/index.htm">http://www.vba.va.gov/bln/vre/index.htm</a>
<b>Independent Living Program: Veterans Affairs</b>	<a href="http://www.vba.va.gov/bln/vre/ilp.htm">http://www.vba.va.gov/bln/vre/ilp.htm</a>
<b>Life Insurance: Veterans Affairs</b>	<a href="http://www.insurance.va.gov">www.insurance.va.gov</a>
<b>Specialty Adapted Housing Program: Veterans Affairs</b>	<a href="http://www.homeloans.va.gov/sah.htm">http://www.homeloans.va.gov/sah.htm</a>
<b>Traumatic Injury Protection Under Servicemembers' Group Life Insurance (TSGLI)</b>	<a href="http://www.insurance.va.gov">www.insurance.va.gov</a>
<b>Army Wounded Warrior Program (AW2)</b>	<a href="http://www.aw2.army.mil">www.aw2.army.mil</a>
<b>U.S. Marine Corps Wounded Warrior Regiment</b>	<a href="http://www.woundedwarriorregiment.org">http://www.woundedwarriorregiment.org</a>
<b>NAVY SAFE HARBOR--Severely Injured Support</b>	<a href="http://www.npc.navy.mil/safeharbor">www.npc.navy.mil/safeharbor</a>
<b>Air Force Wounded Warrior AFW2</b>	<a href="http://www.woundedwarrior.af.mil">http://www.woundedwarrior.af.mil</a>



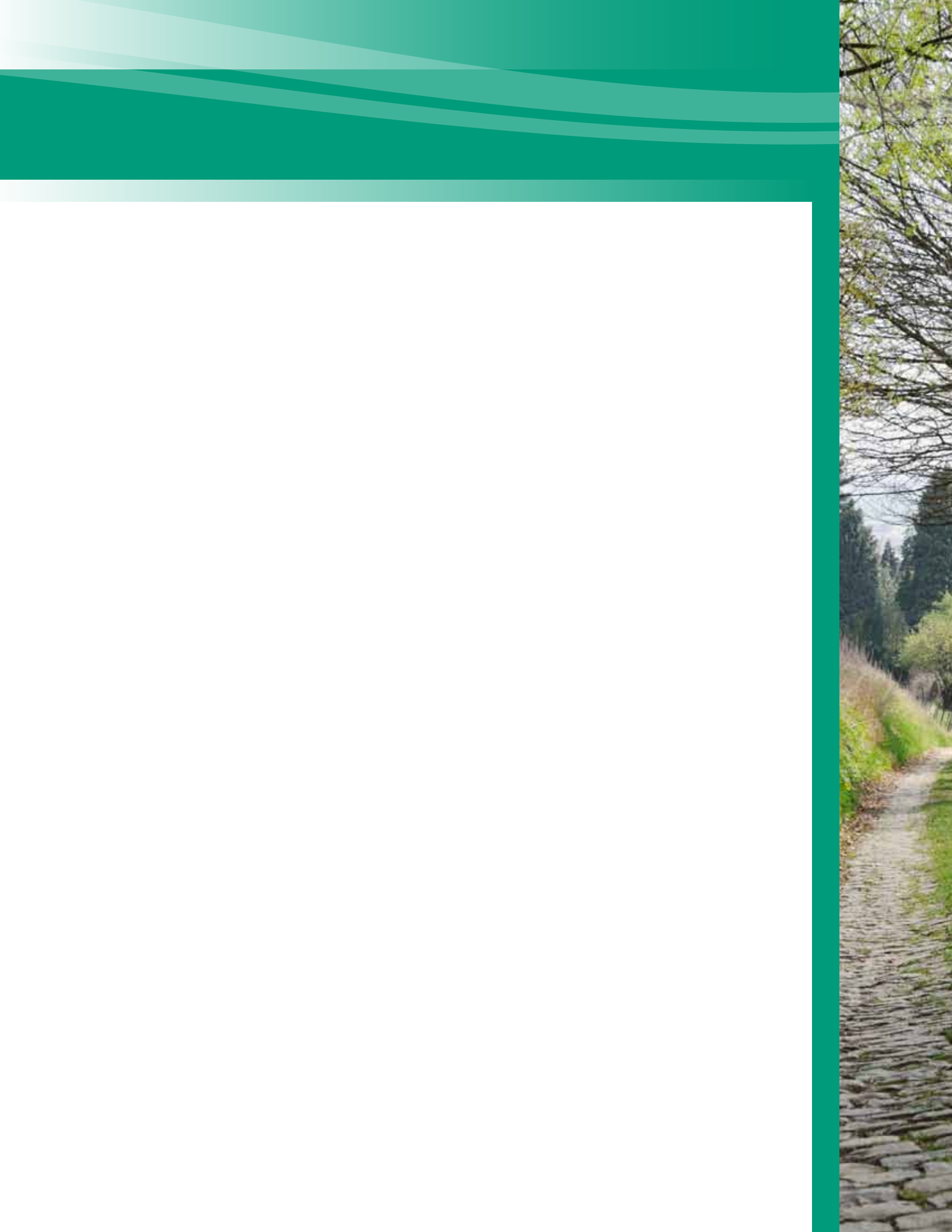


## Journal

*The questions below can help you reflect on your experience as a caregiver. You can write your thoughts here, copy this page and add it to your journal if you keep one, or reflect on these questions in your journal.*

*How has your relationship with your service member/veteran with TBI changed?*

*Are you experiencing conflicts with other family members? Describe each person's point of view in the conflict. List strategies that you could use to resolve the conflict.*



## Transitioning to Home

The transition to home can be an exciting step, but it also can be stressful. Remember, you do not have to do it all yourself. Plan and prepare before your family member comes home.

If possible, try a practice weekend at home. A practice weekend will alert you to how much help you may need. Talk with your health care team about the transition to home and make a plan.

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*"We had gotten a pass to come home for a visit. The kids were so excited to see their dad. Then when we came home for good, they were really excited to have dad back at home."*

- Aimee W.

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Your Point of Contact(s), case manager(s), VA liaison, and/or military liaison are the point persons for helping you transition to home or another facility. They help identify available resources of regional and national services for which you or your family member with TBI may be eligible. (See Module 4 to learn more about Points of Contact.)

You are providing a very important service to someone you care about. This chapter will provide information about:

Managing TBI care at home, by:

- tracking treatments, and
- managing medications.

Organizing:

- your caregiving tasks
- supportive family members and friends who can help
- your home life to take care of your service member/veteran with TBI.

Asking others for help is not a sign of weakness and it makes good sense. Asking for help is a good way to find resources that will support you and your service member/veteran throughout the recovery period.





*"The biggest challenge? Just the stress of being the only person. It's hard most days. Being everybody's memory and being everybody's person that does everything, that cooks and cleans, and makes sure everybody gets where they need to go, and everybody remembers where they need to go. It's overwhelming for the most part.*

*You kind of wish that you had more of a partner than somebody you're taking care of, but it's not their fault. They can't help it. They were just doing their job."*

- Emily S.

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### **Before your service member/veteran with TBI goes home from the hospital:**

- Ask the Point of Contact (POC), case manager(s), VA liaison, and/or military liaison about resources your family member will qualify for from the federal, state, and local government. (Learn more about POCs in Module 4.)
- With the help of your health care team, write a master schedule for your family member. An example is included on the next page.
- Ask for a written list of all therapy and exercises (diagrams or pictures of the exercises) to be done at home.
- Ask for help. Seek out people who offered to help and ask them to be available (See page 54 for more tips.)
- Identify services available in your community you can contact for help. The National Resource Directory ([www.nationalresourcedirectory.org](http://www.nationalresourcedirectory.org)) may be helpful. Local brain injury, veterans support groups, and chapters of the Brain Injury Association can also be good resources. (See Appendix.)
- Prepare yourself and your home before your family member with TBI arrives. If your family member has physical disabilities, your health care team may be able to do a home safety evaluation.
- The Department of Veterans Affairs (VA) and some charities have programs that will modify your home to accommodate your service member/veteran's needs.

- Decide what projects and chores can be put off for a while; give yourself permission not to do it all.
- Make a list of the assistive devices your family member is using in the hospital. Ask the case manager to make sure you will have the same assistive devices at home. Be sure you have prescriptions written for devices needed at home.
- Know who on the health care team to call for what and post it at home. You may wish to use the form at the end of the chapter (page 64) to organize contact information for the health care team.
- Make plans to give yourself a break each day. Have someone come to the house, so you can get out for a breather. (See Respite Care, page 60.)

### What to Expect

- Know that your family member with TBI will do best with structure, consistency, and a schedule.
- Stick to your master schedule (see sample below), so you don't have to rely on your memory during this time of transition.
- People with TBI often get more confused. Their behaviors and cognition problems may appear worse for a while after a change—even if it's a good change. Your family member will settle in over time, just as you will.

#### MASTER SCHEDULE

*Sample Weekday Activity Schedule – tailor this for your family member's specific needs*

8:00 a.m. – 9:00 a.m.	Breakfast, Take Medications
9:00 a.m. – 10:00 a.m.	Dressing, Toileting, Grooming
10:00 a.m. – Noon	Physical Therapy Activities & Rest
Noon – 1:00 p.m.	Lunch, Bathroom, Rest
1:00 p.m. – 4:00 p.m.	Communication Therapy/Occupational Therapy/Therapeutic Recreation* & Rest
5:00 p.m. – 6:30 p.m.	Dinner, Take Medications
Evening	Leisure Activities
9:00 p.m.	Bed Time Activities

\*Rotate activities as recommended by therapists

*Living with a TBI usually means taking multiple medications to treat the symptoms.*

## How Do I Manage Care at Home?

### How Do I Manage Medications?


It is important to keep track of what medications are being taken and when.

Here are tips to manage medications and prevent mistakes:

- Always inform all members of your health care team of any drug or latex allergies.
- When you leave the hospital or treatment facility, be sure you get a copy of the discharge instructions. They will include a list of all the medications your service member/veteran will be taking.
- When picking up prescriptions from the pharmacy, have the pharmacy provide written information about the current prescriptions.
- When picking up the prescription, make sure the order has your family member's name on it. Make sure it includes the correct pills at the right dose.
- Ask the doctor and/or pharmacist
  - what the medication is for, what it does
  - what to do if you miss a dose
  - when/how to take it (empty or full stomach, day time or bed time)
  - what to do if there are side effects.
- Make sure the doctor is aware of all other medications. This includes supplements and herbal products that your family member takes. There might be possible side effects or harmful interactions.
- Keep an up-to-date medication log with all prescription and non-prescription items. Include over-the-counter medications like antacids, pain relievers, supplements, high energy drinks, and herbal products.
- Carry the medication log (page 7) with you every time you have a medical appointment.
- Use a pill box to help you organize the medications and to help your family member take them on time.
- It is never a good idea to stop medication on your own; always consult a provider first to discuss.
- It can also be dangerous to adjust the dosage of medications on your own, without consulting the physician.
- If you are having financial difficulties that make it hard to pay for medications, contact your case manager.





- 
- Your family member with TBI should NEVER take any medication without talking to the health care provider first.

### Tips for Tracking Treatments and Side Effects

- List side effects of medications (date and time) on the medication log at the end of this chapter. Ask the doctor which side effects are serious and call immediately if they occur. More information on side effects can be found in Module 2.
- Write down results of tests (such as blood pressure, blood sugar, and/or medication blood levels). If you are checking your family member's blood pressure or blood sugars at home, write down the values.
- Be sure to take these results to appointments with health care providers.

### Does My Family Member Need an Assistive Device?

For people with TBI, it can be a challenge to accomplish daily tasks such as talking with friends, going to school and work, or participating in recreational activities. **Assistive devices** can make it easier for a person with a disability to manage these activities.

**Assistive devices** can be anything from simple to complex devices such as:

- a magnifying glass
- a timer to remind the person when to take medications
- a touch-fastener grip attached to a pen or fork for eating or writing
- a PDA (Personal Data Assistant)
- a special telephone that helps people with speech and hearing problems to communicate
- braces, splints
- canes, walkers, crutches
- calendar or memory notebook for tracking appointments, planning, organizing
- medical alert bracelet or emergency call system
- eye patches, prism glasses
- special beds.

Keep the phone number for equipment companies available for emergencies or machine malfunctions.

*Assistive devices are tools to help your service member/veteran be more independent.*

*Your home may need to be altered to make it more livable.*

Your family member with TBI will be evaluated during rehabilitation to see if assistive devices would enhance his or her independence and capabilities.

Find out if the devices being used during inpatient stays should be included in the discharge plan. Devices prescribed by a provider are more likely to be funded by the military, VA, or insurers.

### Does My Home Need to be Modified?

Home modifications may be relatively minor and inexpensive, such as installing grab bars, handrails, and lever handles. They may also be major and very expensive, such as:

- installing elevators or lifts
- enlarging doorways to allow wheelchair passage
- modifying kitchens for easier meal preparation
- installing emergency communication systems.

Don't rush into major modifications because your service member/veteran's needs may change over time.

Ask the health care team what, if anything, needs to be done to modify your home before your family member is discharged. You can plan other modifications as his or her rehabilitation continues.

See Module 4 for resources to assist you with home modification.

## How Can I Organize to Get Help with Caregiving?

Here are some steps to consider in organizing your home life:

- Identify family, friends, or those in the community who can assist you in the home.
- Ask a friend or adult family member to read this section and assume the role of coordinating the **Home Care Team**. This will take a load off your mind, even if it is short-term help. You can work together to get the outside help you need.

### Your Home Care Team

- Family members
- Friends
- Members in the community
  - Faith organizations
  - Local charities
- Home health care providers

*A Home Care Team are the friends, family, and others who will help you do all that needs to be done at home to care for your family member with TBI.*

- Outline your tasks. Not just tasks to take care of your service member/veteran with TBI, but tasks that lighten the load for you and other members of the family.

Don't feel like you need to do everything.

### What Needs to be Done?

Your new "normal" day will now consist of your usual everyday tasks, plus the care and treatment tasks for your family member with TBI. These care and treatment tasks may take up much of your time.

Your Home Care Team may be able to help you with many everyday tasks and possibly some of your family member's care tasks. A possible listing of tasks appears below. If you ask your children for help, be sure the tasks you give them are age-appropriate.

### Creating your Home Care Team

- Bring family members and friends together, and request their help in caregiving.
- It is important to accept help because it's not likely that you can do it all yourself.

*Though it may be difficult to ask, find people who are willing to help.*

Type of Task	Specific Task	Who Can Do This Task /Resources	Community Resources
Everyday Tasks	Food Preparation Housework Finance/Insurance Transportation	Family members Neighbors Friends	<a href="http://www.fianationalnetwork.org">http://www.fianationalnetwork.org</a> <a href="http://www.VFW.org">www.VFW.org</a>
Care Tasks	Medical Appointments Supervision Personal Hygiene Medical/Nursing Care	Caregiver Family members Hired home care aides	<a href="http://www.legion.org/veterans/h2h/about">www.legion.org/veterans/h2h/about</a>
Other	Support for Recreation/ Employment/ Education/Legal	Veterans service organizations, religious organizations, workplace, social group/clubs	<a href="http://www.ourmilitary.mil">www.ourmilitary.mil</a> <a href="http://www.purpleheart.org">www.purpleheart.org</a> <a href="http://www.DAV.org">www.DAV.org</a>





*"Pat's family did a lot of research for me as far as different things that were available. I really didn't do a lot of it myself because I was at the hospital. They were trying to find ways to help.*

*I just think one of the best things I did for Pat is opening up about his injury to everyone and letting everyone support us. I know the head injury has a lot of things that can go on and maybe things that are embarrassing that you don't want people to know. We started a family Web site—I write everything that's going on as a way for me to keep track of his progress and to let people know what we need and how he's doing. It's been like a record for me.*

*We still have people involved. I think that's really important, to let your friends in. Let them help you. Let your family help. Let them be a part of the recovery, because when you see them, you can see it in their eyes. They've been as much a part of it as you have. I just think that's really important."*

- Patty H.

- If you do not have time, have a family member or friend help you organize your Home Care Team.
- If possible, ask your family member with TBI which people he or she would like involved.

## How to Ask for Help

Tips for asking for help from others:

- Write down the names of those who offer. See the Possible Home Care Volunteer form at the end of the chapter to keep track of possible volunteers. (A copy of this form can also be found in the Caregiver's Companion.)
- Make a list of everyone close to you and your service member/veteran who can be part of your caregiving team.
- Make sure word of the injury gets out to any groups, social organizations, and faith organizations to which you and your service member/veteran belong.

Some people find it really tough to ask for help. If that's you, put yourself in the shoes of a family who needs help. You would most likely be willing to help them if the tables were turned. So, tough as it may be, let them help you. If you're too stressed to even think about organizing others to help, ask a friend to take on this role.

- Gather lists of names, phone numbers, and e-mail addresses, and add these names to your list.
- Check into organizations that specialize in helping:
  - America Supports You/U.S. DoD Community Relations ([www.OurMilitary.mil](http://www.OurMilitary.mil))
  - Faith in Action National Network ([www.fianationalnetwork.org](http://www.fianationalnetwork.org))
  - Heroes to Hometowns ([www.legion.org/veterans/h2h/about](http://www.legion.org/veterans/h2h/about)). (See Appendix.)
- Once you have a list of names, call or create an e-mail group based on your list of names to invite others to help.
- If you do not have a computer or don't know how to use one, ask a friend who is tech savvy to help you send out a group e-mail.
- Keep a large calendar near the phone. As you schedule others to help, jot down their names and the tasks they will do. Do not rely on your memory.
- Ask for specific help. For example, ask someone to go grocery shopping or come over and spend time with your service member/veteran while you go out to do something for yourself.

*"We were fortunate in two regards. One, we have a very close family. They were all there for us whenever we needed them. Our neighbors would keep our 13-year-old daughter when Mike and I had to fly out. So we had a really good support group as far as people wanting to help. If it meant bringing a meal over, that's what they did."*

- Pam E.



*Suggestions for  
coordinating your  
Home Care Team.*

## **Coordinate Your Home Care Team**


- Consider holding a meeting for all Home Care Team members to discuss the specifics:
  - issues regarding the injury and your family member's needs
  - current needs of your family member with TBI and the rest of your family
  - the roles or tasks each team member can take
  - exchange of contact information
  - members' availability and tasks they are willing to do (write these down)
  - identification of a team leader to make phone calls to team members during emergencies or to re-organize schedules.
- Invite potential Home Care Team members to the hospital or rehabilitation center to learn more about TBI and your family member's specific needs.
- Manage Home Care Team schedules on a master calendar (keep this in your home).
- Have an easily visible list of important information:
  - location of pharmacies
  - grocery stores
  - medical information
  - list of phone numbers of people to contact in an emergency.
- Have some cash available for helpers in case of emergencies, an extra set of house keys, and a spare set of vehicle keys.

## **Create Routine in Tasks**

- Set up chore lists, schedules, meal menus, grocery lists as things run out, etc.
- Create and document routines. You relieve yourself of having to constantly make decisions that take up time and emotional energy.







You can keep your family, friends, and Home Care Team updated on progress by creating a personalized Web page at sites such as [www.carepages.com](http://www.carepages.com) or [www.caringbridge.org](http://www.caringbridge.org). These are free. Web pages are easy to set up and give you the ability to provide updates on your service member/veteran's progress, get support, coordinate care, and share information—all in a short e-mail note. Your family and friends can send you and your service member/veteran notes of inspiration and friendship.

Many families ask someone outside of the immediate family to establish the Web page and then this person shows the family how to do updates, which is simple. Most hospitals/rehab centers have computers for families to use to make the updates. These Web sites greatly reduce the burden on families in telling the same story and updates over and over on the phone, which can be emotionally and physically exhausting.

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*"This is another tool, caringbridge.org. Originally when the injury occurred, all the family was calling. It was just too overwhelming. I couldn't call everybody every day. So the people at the Fisher House in Landstuhl, Germany told me about this Web site. It was great. You could download pictures, and set up a Web site for your injured soldier and fill it out. Every day I went on there to write my daily journal. That was the journal that I kept."*

- Cindy P.



*Respite care is “planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver.”*

*Where can you find respite programs?*

## Time Management

There may be more to do than you have time and energy for. To help manage your time, the following will help you prioritize:

- Decide which tasks need to be done right away and which tasks can wait until later.
- Prioritizing allows you to focus on those tasks that absolutely need to be done. Delegate others to your Home Care Team members.
- You can do the urgent and important tasks. Schedule your Home Care Team members to do the “not so urgent” important tasks.

## Time Off: Respite Care/Day Programs

The demands of being a caregiver may cause many challenges. Respite – time off – care helps both the caregiver and service member/veteran in living with brain injury.

**Respite care** is a valuable resource to you and your family member.

Respite care offers a break and allows you time for yourself.

A companion or sitter may provide respite at home.

Respite may be provided outside of the home in an adult day care or assisted living or nursing facility.

It can range from a few hours per day, a week, or short-term placements.

Day Rehabilitation Programs may help your family member remain in the home.


These programs may also provide meaningful, engaging, structured activities during the day while you go to work outside the home.

Respite services for persons with TBI are generally supported by government grants and contracts, nonprofit agencies, Medicare, Medicaid, and through self-pay (most often sliding scale fees).

Many VA Medical Centers offer respite care and day programs. See Module 4 for additional resources.

TRICARE provides respite care for homebound service members on active duty who meet the following criteria:

- their conditions or injuries make them unable to leave home without taxing effort
- they need more than two interventions during the eight-hour period per day when the primary caregiver would normally be sleeping.



For these individuals, TRICARE provides a maximum of eight hours of respite per day, five days per week. This benefit is retroactive to January 1, 2008, and has no cost shares or co-pays. For more information, consult [www.tricare.mil](http://www.tricare.mil).

The National Resource Directory ([www.nationalresourcedirectory.org](http://www.nationalresourcedirectory.org)) can direct you to respite programs. Your religious community, local social service agency, local chapters of Easter Seals, the local mental health agency, military service organizations, veterans service organizations, and Military OneSource's Wounded Warrior Project (see Appendix) are all organizations that can help you find the right respite care for you.

Ask your Point of Contact/case manager about the Exceptional Family Member (EFM) Respite Care Program, and how to qualify. More information can be found at <http://www.MyArmyLifeToo.com> and <http://www.militaryhomefront.dod.mil>.

*There are many organizations that have respite care. This list may be useful:*

#### **Exceptional Family Member (EFM) Respite Care Program**

##### **Army**

40 hours of respite care per month per EFM

- Family selects respite care worker
- Monthly Respite Care Newsletter: <http://www.MyArmyLifeToo.com>

##### **Navy**

- **Goal** to assist sailors by addressing the special needs of their family members during the assignment process
  - **Navy EFMP Coordinators** are located at Navy medical treatment facilities. Their role is to refer to the Fleet and Family Support Center for community assistance
    - Special medical, dental, mental health, developmental or educational requirements, wheelchair accessibility, adaptive equipment, or assistive technology devices and services
- <http://www.militaryhomefront.dod.mil>

##### **Marines**

- 40 hours/month
- Care can be provided by
  - Installation CDC
  - FCC Home
  - Visiting Nurse Service
  - Family member
  - Neighbor.



- **National Association of Child Care Resource & Referral Agencies (NACCRRA)**
  - Partnership Program with Marine Corps EMFP Respite Care
  - 40 hours/month of free respite child care
  - 10 participating bases
- **Air Force Aid Society Respite Care Program**
  - Respite Certificate issued with number of hours of respite over three month period
  - Services are re-evaluated quarterly
  - 4-6 hours/week – average
  - Family identifies care provider
  - Will not reimburse for a relative to provide care.

## Home Health Care

Home health care is care for your family member with TBI from a qualified aide, nurse, and/or therapist in your home. You may be eligible for assistance with home health care from TRICARE, the Department of Veterans Affairs, or Medicare (see Module 4). If not, you may choose to pay out of pocket or use other health insurance your family member may have.

- There are many professional agencies that offer home health aide services; if you are eligible for government assistance, you may need to use an approved agency.

If you use an agency:

- You may pay more per hour, but the agency assumes the employment responsibilities. It bonds and certifies the home health workers.
- It also provides substitutes for sick days.

If you choose to hire privately:

- The advantage is that you can usually pay less per hour for help.
- However, this means you are an employer and must adhere to all employment laws, including payroll taxes and Workers' Compensation insurance. Your state Employment Development Department will help you set up the necessary paperwork.

On the next pages are forms that you can duplicate and use to record information to make caregiving easier. (These forms can also be found in the Caregiver's Companion.)




### Home Care Team Volunteer Form

Name	Contact Information	What he or she would like to do

## Contact Information of the Health Care Team Members

PROFESSIONAL - NAME	CONTACT INFORMATION
Audiologist	
Cardiologist	
Case Manager(s)	
Chaplain Services	
Department of Defense Military Liaison	
MEB/PEB Case Manager	
Neurologist	
Neuropsychologist	
Neurosurgery Specialist	
Nurse	
Occupational Therapist (OT)	
Ophthalmologist	
Optometrist	





PROFESSIONAL - NAME	CONTACT INFORMATION
Orthopedic Specialist	
Physiatrist (Physical Medicine and Rehabilitation Specialist)	
Physical Therapist (PT)	
Plastic Surgeon	
Primary Care Provider	
Recreational Therapist	
Registered Dietitian	
Rehabilitation Nurse	
Rehabilitation Psychologist	
Social Worker	
Speech/Language Pathologist	
Urologist	

## Caregiver Support Worksheet

Caregiving Task	Who Can Help	Contact Information
<b>Everyday Tasks:</b>		
Meal Planning		
Lawn Care		
Grocery Shopping		
Meal Preparation		
Light Housekeeping		
Transportation for:		
Other Family Members		
Shopping & Errands		
Child Care		
Pet Care		
<b>Care Tasks:</b>		
Coordinating Home Care Team		
In-home Supervision/Companionship		
Transportation for:		
Medical Appointments		
Support Group/Counseling		
Care Team Meetings/Dinner		
Personal Hygiene:		
Bathing		
Other, e.g. hair, nails, skin		
Hands-on Medical Treatments/Exercise/Therapy		
Scheduling Medical Appointments		
Managing Medications		

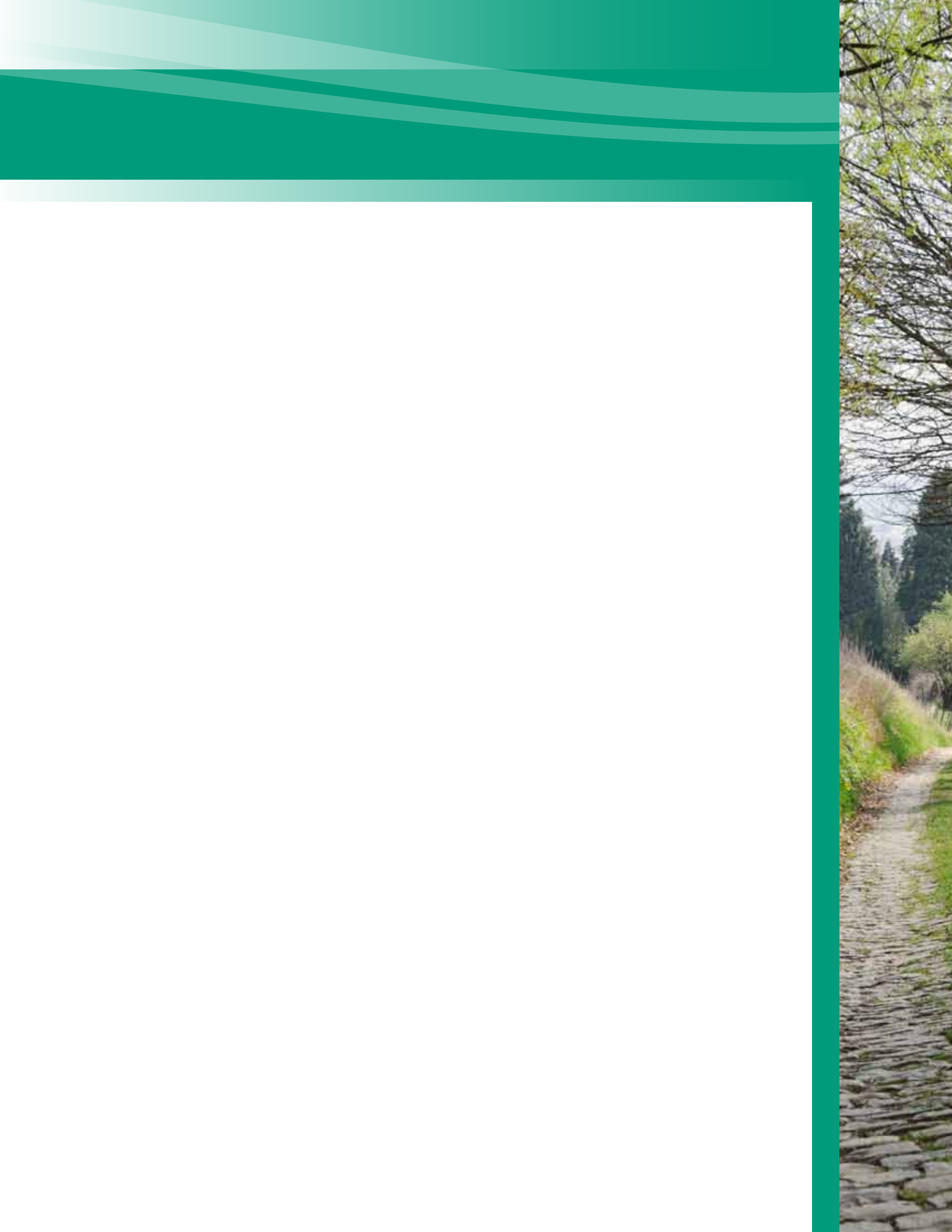
Caregiver Support Worksheet

Caregiving Task	Who Can Help	Contact Information
<b>Recreation Activities</b>		
For the Service Member/Veteran		
For the Family Caregiver		
For Other Family Members		
<b>Finances/Legal</b>		
Banking		
Paying Bills		
Managing Military/VA Benefits		
Managing Insurance Claims		
Handling Legal Matters		
Finding Community Services		

Becoming a Family Caregiver for a Service Member/Veteran with TBI

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## Moving Forward

Each person's experience with the effects of TBI is unique. Most effects improve with time, although some may linger for a lifetime. Only time will tell.

As you are now aware, brain injury presents many challenges for survivors and their families. For many, recovery will extend over a lifetime. There is no "normal" time frame for recovery. Many family members with severe injury surprise doctors with an unexpected degree of improvement.

Many factors determine the extent of recovery. The more severe the damage to the brain, the greater the likelihood of long-term problems. Pre-injury history plays a role in how the individual will adapt and accept these changes.

However, with the passage of time, a dose of patience, and a strong support system, most individuals will go on to productive and fulfilling lives.

Returning to the community, to family, and to school or work following a TBI can be challenging. It is possible. For most family members with TBI, the possibility is what drives family members with TBI to work hard in therapy.

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*"It does get better. I don't know if it gets better because you get used to it or because they are making improvements. Jason has definitely made improvements. We've kind of fallen into a routine, and I guess when you fall into a routine, then you know what to expect. I guess that makes it easier. It does get easier, just because they're getting better, and they do get better."*

- Pam E.

*"He's been really good. He's been going to his appointments all by himself. He tells me what happened at the appointment, and what kind of drugs they give him. I really couldn't tell you exactly what his medications are unless I look in the cupboard. He is to the point where he is doing it himself."*

- Kristen S.



*Everyone who experiences a TBI wants to get back to “normal” life as soon possible.*

## What Can I Expect When My Family Member Comes Home?

- For most of us, a “normal” and fulfilling life usually includes things like living independently, spending time alone, working, attending school, volunteering, driving, doing household chores, parenting, dating, and participating in social and leisure activities of our choosing.
- For a person who has recently experienced a TBI, some or all of this may not be possible right away. The hope is always there that most will be possible, over time.
- Moving back home is an exciting step in the recovery process! Although the transition to home is certainly positive, it is important to be aware that it may also be stressful at times.
- There is no way to prepare yourself for what lies ahead. With time, most people with TBI and their families successfully adjust to life at home.
- Some families report that during the first few days or weeks at home, their family member actually seemed to have taken a step or two backwards. Your family member with TBI needs more time than he or she used to in order to adapt to a new environment, even if it’s a familiar one.
- Returning to the community, to family, to a familiar setting requires thoughtful planning to insure that the transition goes smoothly. It is important that you work closely with the rehabilitation team to prepare a discharge plan.
- Skills that your service member/veteran acquired or relearned in rehabilitation do not easily transfer into a home setting without a great deal of support and reinforcement. The therapy team will spend weeks to months preparing you and your family member for this step.
- You will both have many opportunities to practice and to identify what the challenges might be BEFORE you go home.

Those with TBI prefer structure. They adjust better and thrive when there is some routine and predictability to their days. It is helpful to add structure right away at home by scheduling activities and rest breaks much like the schedule observed in rehabilitation.

- Over time, as everyone adjusts to being home and your service member/veteran continues to recover and gain skills, the need for so much structure may lessen and more flexibility will be possible.





- Your family member may be concerned that he or she cannot easily make comfortable relationships with other people because of the cognitive and communication effects of TBI. You may be worried that he or she will behave inappropriately or unsafely because of reduced judgment or impulsivity.
- Role play potential social situations with your family member with TBI before he or she ventures into community settings. This helps in understanding appropriate behavior.
- You may also find it useful to help your family member with TBI prepare for and organize trips into the community. Recreational and occupational therapists are your best allies in this effort and they will work closely with you to practice community re-entry.
- You can find more information about programs from the Department of Veterans Affairs to assist your service member/veteran with TBI re-integrate into the community in Module 4.

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*"My son volunteers at an elementary school. He loves children. He volunteers on Monday and Wednesday with his TBI team. He assists the physical education teachers twice a week for three hours.*

*He also volunteered at an animal shelter, and he would help walk the dogs, bathe them, and sometimes they'd let him give an injection. He has come a long way. I think they're giving him different options for the future. You know, volunteer work, what he can do with his life every day, how he can keep himself busy and keep using his skills. We all know, if you don't keep using it, you're going to lose it. So it's important to keep him busy."*

- Cindy P.

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## How Can I Protect the Safety of My Service Member/Veteran with TBI?

- Use the Home Safety Checklist at the end of this chapter to assess the safety of your home. Your physical therapist and occupational therapist (PT/OT) will work with you to decide if you need to make safety modifications to your home. Talk to your PT/OT to learn about what other resources might be available through VA.
- Be sure to remove or secure items from your home that could result in harm to your family member with TBI. For example, keep car keys put away if your family member is not cleared to drive.
- Avoid keeping guns, knives, or other weapons in the house.
- When your service member/veteran with TBI begins expanding his or her activities beyond the house, it is important that he or she carry identification at all times.
- Some may choose to continue wearing dog tags but other forms of identification should be carried on his or her person, such as a MedicAlert bracelet or necklace. This will help insure that all medical information is readily accessible to emergency medical personnel if it is needed.
- A cell phone, programmed for voice activation, can be a lifeline for those who have trouble reading numbers or text.
- Depending on level of cognitive and functional ability, 24-hour care may be needed to ensure safety. Your family member will be evaluated for his or her ability to live alone with or without help.
- Ask the OT/PT to help with fall prevention if your family member has trouble with dizziness and balance.
- Removing clutter and simplifying your home environment can help a person with TBI. Clutter—too many things in the visual environment—can contribute to a sense of overstimulation.
- Clutter raises the likelihood that there are things that your family member may trip over or bump into, especially if he or she is experiencing balance or vision/perception problems.

## Can My Family Member with TBI Drive?

Driving is a key mark of independence in our society. Your family member may be eager to get behind the wheel again.





A professional should evaluate your family member's ability to drive. This evaluation is usually done by an occupational or physical therapist, a neuropsychologist, or a certified driving evaluator.

Good vision and good perceptual skills, such as the ability to judge distances between cars, are required to drive safely.

The evaluation will address the following skills as they relate to driving:

- Physical skills –
  - ability to physically steer and brake the car, and control speed
  - assessment of need for assistive devices for driving
  - ability to get in and out of the car
- Visual/spatial skills –
  - assess need for corrective lenses
  - be able to concentrate attention in his or her central vision
  - good peripheral vision
- Perceptual skills –
  - the ability to judge distances between cars on the road and space in parking lots
  - ability to interpret complex visual information, such as following verbal directions to a store
  - recognize shapes and colors of traffic signs
  - left/right neglect, no drifting to one side of the road
- Speed of motor responses –
  - reaction time
  - ability to brake or change lanes safely within a reasonable amount of time
  - ability to process a lot of information and react quickly
- Judgment –
  - adequate decision-making skills in an emergency
  - possess a healthy self-awareness and an understanding of his or her strengths and weaknesses.
- As cognitive skills improve, driving skills may be re-evaluated. Many people with TBI do eventually return to driving and drive safely. Driving skills affected by TBI can be improved through training that focuses on visual scanning, attention skills, and spatial perception.

*Driving involves a large number of skills and the ability to integrate complex information very quickly.*

*An evaluation of your family member's ability to drive is crucial.*



- Professionals certified through the Association for Driver Rehabilitation Specialists can provide evaluation and training. A list of experts is found at [www.driver-ed.org](http://www.driver-ed.org).
- In some situations, the loss of skills needed to drive safely may prevent the person from driving again. When this occurs, it is important for the doctor or another appropriate professional to insure that the family member with TBI and other family members understand the reasons.
- The family must be diligent about enforcing the “no driving” rule. For example, you may need to keep close control of the family’s car keys.
- If your family member cannot drive a motor vehicle safely, there are other transportation options. Public transportation (bus, train, subway) may be available.
- Resources for transportation to medical facilities for appointments, to obtain medications, or other needs may be obtained from a variety of sources, such as the Department of Veterans Affairs, Medicaid, Community Transportation Association of America, or Disabled American Veterans.
- Consider driving assistance from family members, friends, church, or community groups.

## Should I Be Concerned about Alcohol and/or Drug Use?

*There is no safe amount of alcohol to consume after a brain injury.*

- Some people with TBI turn to alcohol and/or drugs to help them cope with the effects of their injury. This coping strategy for a person with TBI can be very harmful and is never a good idea.
  - After a TBI, the brain is more vulnerable to the effects of alcohol and drugs so the person will feel these effects much more quickly.
- Alcohol and other non-prescription drugs can slow down the recovery of your service member/veteran with TBI in the following ways:
- make it harder for the brain to heal
  - interfere with thinking processes that are already slowed down
  - interact negatively with prescription medications
  - increase aggressive and socially inappropriate behaviors
  - increase balance problems
  - promote other risky behaviors
  - create greater risk for seizures



- increase problems with the law for public drinking
- cause addiction
- cause problems with friends and family
- worsen feelings of depression and anxiety
- put your family member and others at risk for falls, car crashes, and other accidents that can lead to another TBI or worse.

Cognitive difficulties and decreased awareness make it more difficult for your family member with TBI to recognize that alcohol and drugs have a negative effect on him or her.

Take an active role in helping your service member/veteran with TBI avoid alcohol and drugs. You might:

- Talk with him or her about readiness to change drinking or drug use. Help your family member make a list of pros and cons of using substances.
- Spend time with those family and friends who are supportive of your service member/veteran not using substances. Minimize time with those who are not supportive.
- Avoid high risk situations, such as people or places that your service member/veteran associates with drinking or using drugs.
- Develop a plan to help your service member/veteran cope with tempting situations, such as leaving the situation or calling a supportive friend.

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*"There are situations where he wants to go out with the guys. What are 23-year-olds going to do? They're going to go out and have a drink. With a brain injury, that's not good because it can affect his recovery, and he knows that. But he's one of the guys and he doesn't want to be singled out. He wants to fit in. So it's very difficult.*

*What I do is tell his friends that they're responsible for his well-being. I just keep reminding him, and I try to make sure that he's in situations that are safe and that are going to be successful."*

- Cindy P.



- Explore new social circles or environments that do not involve drinking.
- Encourage learning of new ways to deal with stress (see Chapter 4).
- Remove alcohol and other dangerous substances from the home.
- If depression or boredom or loneliness are reasons for use, seek counseling and other services.
- If your service member/veteran has recently quit using substances, talk openly with him or her about the possibility of using again in the future and stress that one “slip” does not need to mean a return to regular use. Encourage use of support systems to help avoid a full relapse.
- Locate a local AA group or treatment program if advised by your health care team.

Use of alcohol should be discussed with the health care team before leaving the rehabilitation facility.



*“The one thing that’s been so good for my son is running marathons. When he was at the Wounded Warriors battalion, he was volunteering for Hope For The Warriors. They got him a trainer, and they set him up to run the Marine Corps marathon. They trained him and got him into running, which my son had always hated.*

*He’s constantly running and training. He’s training again for the Marine Corps marathon. He knows that when he’s training, he cannot drink and train. It just doesn’t go together. So that’s a wonderful way to keep the drinking away.”*

- Cyd D.





## How Can My Family Member Avoid Another TBI?

- Repeated blows to the head result in further damage to the brain. The effects of repeated injuries to a brain that has sustained a previous injury tend to add up, causing greater damage than the initial injury. (Think of boxers, football players, and other professional athletes who have become disabled due to multiple TBIs.)
- For this reason, it is best for people with TBI to exercise caution and avoid another TBI, if possible.
- You can help your service member/veteran with TBI avoid another injury by:
  - safeguarding your home  
(see the Home Safety Checklist at the end of this chapter)
  - insisting on the use of safe practices  
(e.g., wearing seatbelts in the car)
  - following the recommendations of the health care team on activity restrictions (e.g., no contact sports).

A good rule of thumb is: If they make a helmet for an activity (biking, downhill skiing, rollerblading, motorcycle riding, etc.), everyone in the family should wear one!

*Once a person has experienced a TBI, he or she is at risk for subsequent injury to the brain.*

## Home Safety Checklist

This checklist focuses on safety issues that commonly apply to individuals with perceptual and cognitive problems.

### How To Use This Checklist:

Take this checklist with you and as you WALK through your home with your service member/veteran, carefully check “yes” or “no” for each item on this list.

Any item scored “no” is a safety concern and should be corrected.

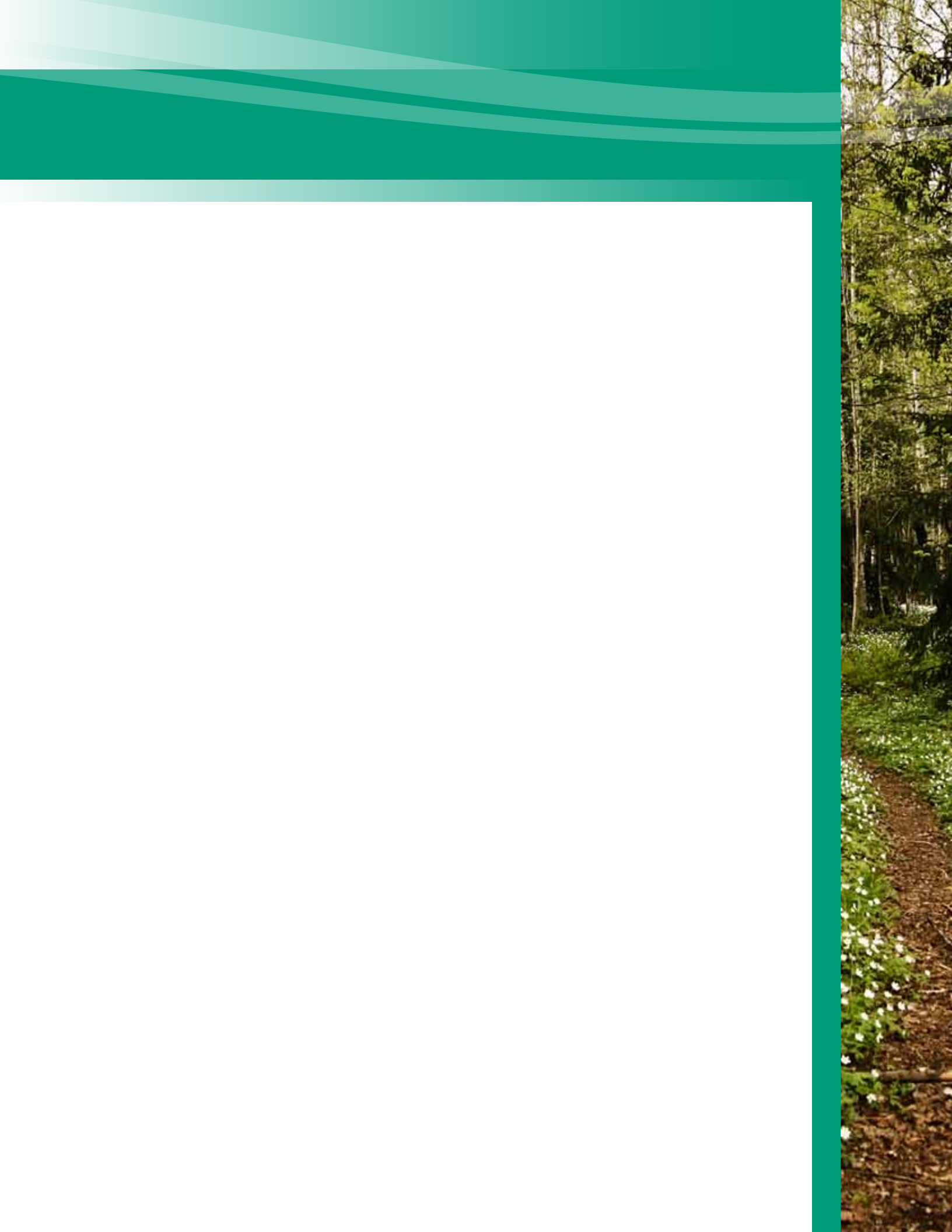
General Home Safety Checklist for Individuals with Perceptual and Cognitive Problems		
Area of Focus	Yes	No
1. While cooking, is a timer available to help you keep track of items cooking on the flame? (attention and memory problems)		
2. Do you use a “whistling” teakettle? (attention and memory problems)		
3. Are commonly used items kept in the same location? (attention and memory problems)		
4. Have commonly used telephone numbers been pre-programmed into the telephone and/or posted near the telephone? (memory problems, sequencing problems)		
5. Do you use a calendar or scheduling book to help remind you of important events? (attention and memory problems)		
6. If necessary, have you posted signs by the door to help remind you to: Lock the front door when you leave Turn off appliances when you finish using them Take out the garbage (attention, memory problems)		
7. Is your front door house key color coded for easy identification? (memory problems, distractibility)		
8. When the doorbell rings, do you use the peep hole to identify who it is before opening the door to let the person in? (impulsivity, decreased judgment)		
9. When necessary, do you utilize checklists with correct steps and sequences for household tasks, such as the laundry or making a bed? (poor attention, memory problems, sequencing problems)		



General Home Safety Checklist for Individuals with Perceptual and Cognitive Problems		
Area of Focus	Yes	No
10. Are directions and steps for multi-step tasks posted at appropriate locations (e.g., near washing machine)? (sequencing problems, difficulty initiating tasks, attention and memory problems)		
11. Are sharp utensils separated from other items and arranged in a kitchen drawer with handles pointing towards you? (perceptual impairments, impulsivity)		
12. Are toxic household cleaning fluids kept separate from other items to avoid potential confusion? (perceptual impairments, attention problems)		
13. Have unnecessary items been removed from the living environment to decrease confusion and distraction? (perceptual impairments, attention problems)		
14. Are commonly used items kept in a consistent, prominent place? (memory and attentional problem)		
15. Are cabinets labeled to assist in locating objects? (memory and attentional problems, safety)		
16. If you are “neglectful” of one side of your body, are objects placed and positioned where you can see and reach them? (perceptual impairments)		
17. Do you use a watch with an alarm and calendar display? (memory problems)		
18. Are the most “taxing” household activities planned for the time of day when you feel most alert and attentive? (attentional problems, fatigue)		
19. Do you have a “Medi-Alert” system in place? (safety, language difficulties)		
20. Does a family member or friend have a key to your home in case of emergencies? (safety)		

If you have answered “YES” to all these items on this checklist, your home appears to be relatively safe. Any items scored “NO” should be corrected to promote a safe home environment. Remember to check with your health care professional to identify any potential safety issues that might be particular to your individual needs.





## Addressing Everyday Issues

This chapter provides information on your rights as an employee, job options for you and your family member if he or she is unable to return to duty, and how to balance work and caregiving.

### What is the Family and Medical Leave Act?

The Family and Medical Leave Act (FMLA) provides service members/veterans and their spouses who are employed by companies with 50 or more employees with up to 26 weeks of unpaid leave per year to care for a seriously-injured service member without losing their jobs or health care insurance.

This act may have small adjustments periodically. Please see the Web site for most current information: <http://www.dol.gov/esa/whd/fmla>.

Check with your company's human resources department about your eligibility for unpaid leave under the FMLA. Know your company's caregiver leave policies. Explore alternative working arrangements, such as flexible hours, working from home, reduced hours, etc.

*You may be eligible to take time off to care for your family member with TBI without losing your job.*

---

*"Our employers did let us work remotely when my husband and I took turns being with our son in Texas. It did get a little dicey there for a little while, but they were very supportive. We were very fortunate. I've talked to many people who just quit their jobs, you know? Some people will just automatically quit their jobs and assume that their employer is not going to be there for them. We have to be here with our son or daughter.*

*Many employers are willing to work with you, too; maybe not indefinitely. But it's certainly an avenue to pursue because it does keep you connected to something a little bit normal, or just to a network of people who just want to be there for you. Both of those things were very helpful to us."*

- Pam E.

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Some states and employers have more extensive policies regarding leave for caregiving. To see what your state policies are, check out:

- Family and Medical Leave Act site: <http://www.dol.gov/esa/whd/fmla>
- National Partnership for Women & Families:  
<http://www.nationalpartnership.org>
- State specific Web sites or offices.

## Can I Receive Public Benefits if I Lose My Job?

- If you lose your job because caregiving is demanding too much of your time, check out unemployment benefits. They can provide some income while you look for other work.
- You may also be eligible for other public benefits such as Temporary Assistance for Needy Families (TANF), Supplemental Nutrition Assistance Program (SNAP, formerly Food Stamps), and Women Infants and Children (WIC) supplemental food benefits (if you have children up to age 5).
- Look in the government pages of your local telephone directory for the appropriate agency that administers these programs in your community.

## Can I Get Help in Finding a Job?


You and your injured family member can get help finding a job. There is support available if you are seeking employment. This support recognizes the important contribution that both you and your family member have made in service to the United States.

Start by checking with your installation's support services. Depending on your service member/veteran's service branch, your Fleet and Family Support Center, Marine Corps Community Services, Airman and Family Readiness Center, or Army Community Service Center can provide you with information and support.

A good starting place is the National Resource Directory ([www.nationalresourcedirectory.org](http://www.nationalresourcedirectory.org)). It is a collaborative effort between the Departments of Defense, Labor, and Veterans Affairs.

The directory is a Web-based network of care coordinators, providers, and support partners with resources for wounded, ill, and injured service members, veterans, their families, families of the fallen, and those who support them.





The Directory offers more than 10,000 medical and non-medical services and resources to help service members and veterans achieve personal and professional goals along their journey from recovery through rehabilitation to community reintegration.

The National Resource Directory is organized into six major categories:

- Benefits and Compensation
- Education, Training, and Employment
- Family and Caregiver Support
- Health
- Housing and Transportation
- Services and Resources.

It also provides helpful checklists, Frequently Asked Questions, and connections to peer support groups. All information on the Web site can be found through a general or state and local search tool.

Other supportive services include:

### **Military Spouse**

The Military Spouse Resource Center ([www.MilSpouse.org](http://www.MilSpouse.org)) is a Web-based service provided by the Department of Defense and the Department of Labor. It provides information about education, training, and employment, as well as child care and transportation.

Also take a look at the Military Spouse JobSearch Web site (<http://www.militaryspousejobsearch.org/msjs/app>). It can help you find companies that are committed to hiring military spouses. It also allows you to search for jobs by the name of a military base.

Military Spouse JobSearch also provides job search resources for people with disabilities, in the event that your service member is not able to return to duty due to disability. Other resources for veterans include federal government positions. The government's Office of Personnel Management provides information on job opportunities for veterans at <http://www.opm.gov/veterans>.

### **Operation IMPACT**

Operation IMPACT was launched by Northrop Grumman. The program provides transition support to service members severely injured in OEF/OIF and helps them identify career opportunities within the corporation. If an injured service member is no longer able to work, the program offers career

*If your spouse is rated with a 100 percent service-connected disability, the Federal government considers you to be an "other eligible," providing the same resources, rights, and services that are available to veterans and disabled veterans.*

*It can be difficult to balance the dual responsibilities of a job and caregiving.*

support to a member of the individual's immediate family who will act as the primary wage earner.

### **Program Eligibility**

*To be eligible for the program, candidates must meet the following criteria:*

- severely injured during combat operations in the OEF/OIF on or after September 11, 2001
- disability rating of 30 percent or greater from the Department of Veterans Affairs.

For more information, contact Operation IMPACT at 1-800-395-2361 or e-mail [operationimpact@ngc.com](mailto:operationimpact@ngc.com) for more details.

### **Federal Civil Service**

- If your family member with TBI is your spouse or child who is a totally disabled, retired, or separated member of the Armed Forces (has been retired with a disability rating at the time of retirement of 100 percent; or retired/separated from the Armed Forces with a disability rating of 100 percent from the Department of Veterans Affairs), you are eligible for expedited recruitment and selection for Federal civil service positions.
- You will be given priority in Labor Department-funded employment and training programs, as well as preference in federal hiring.
- You can search for a Federal civil service position by contacting a One Stop Career Center (find the nearest one at [www.servicelocator.org](http://www.servicelocator.org)). Introduce yourself as the spouse of a recently disabled veteran. Ask to speak with a work force specialist. This individual can tell you about job opportunities in your area.

## **How Can I Balance Work and Caregiving?**

- Talk to your supervisor about your caregiving responsibilities so that he or she understands your need for flexibility. Find out what your company's policies on caregiving are.
- If your firm has an Employee Assistance Program (EAP), you may be able to obtain counseling, legal assistance, and/or referrals to community resources.
- At home, prioritize what needs to be done. Delegate tasks to others. And remember to make time for yourself. You can't help anyone if you get run-down or sick from too much stress.
- If you can't work full-time because of caregiving tasks, look into part-time jobs, flex-time options, and/or job-sharing.

## Planning for the Future

Legal issues to protect your family and your service member/veteran with TBI include:

- Guardianship
- Power of Attorney (POA)
- Medical POA, medical directives
- Trusts
- Life trusts, life insurance, and listing beneficiaries on life insurance policies
- Living wills.

You may need to consider these issues to make good decisions about your family's future. It may also seem hard at first.

Take your time to read this section carefully. It provides the basics of each legal concept. Discuss your personal situation with an attorney or social worker/case manager who has experience with legal matters.

Each state has its own set of rules regarding these legal documents. You will need to find out what the rules in your state are from someone with legal expertise.

### What is Guardianship?

If your service member/veteran is severely injured and unable to manage his or her own affairs and property, you may need to be appointed **guardianship**.

There are three categories of guardians:

- A **Guardian of the Person** ensures the physical care and rehabilitation of the disabled individual.
- A **Guardian of the Estate** (also called a **conservator**) manages the financial affairs and property of the disabled person.
- A **Plenary Guardian** does both.

**Guardianships** are covered under state law. To obtain guardianship over your family member with TBI, you will most likely need an attorney to represent you in court.

You will be required to submit periodic reports and a doctor will need to periodically re-certify that the guardianship is still needed.

*Guardianship is a legal arrangement under which one person, the guardian, has the legal right and duty to care for another, the ward.*





*"I'm the one by his bedside, but I can't make any decisions for my son. We finally went to court and fought, because his wife was the one making the decisions and she wasn't by his bedside. The doctors don't even know who she is. I said, 'How can she make decisions when she's not by his side and she doesn't know what is going on?' So I went to court and I had to fight.*

*Finally the court put in a guardian, a court-appointed guardian for José, and he's the one who makes the medical decisions and the financial decisions for José."*

- Nellie B.

*A Power of Attorney (POA) is a written document in which a competent person, the principal, appoints another person, the agent, to act for him or her in legal and financial matters.*

## What is Power of Attorney (POA)?

Because of decreased cognitive and functional abilities, your family member with TBI may need you or another person to be named **Power of Attorney** to act for him or her in legal and financial issues.


In legal terms, a person is competent when he or she is able to reason and make decisions.

Check to see if your family member has already created a **Power of Attorney (POA)**.

There are different types of POAs:

- A **general power** allows the agent to do any act or exercise any power on the principal's behalf. Only use a general power when a special power is insufficient.
- A **specific or special power** limits the agent's authority to only the act or acts listed in the POA document.
- A **durable power** of attorney permits the agent to continue to act on the principal's behalf if he or she is incapacitated.

A Power of Attorney is created when the principal (your family member) signs a notarized document that legally authorizes another person to act on his or her behalf.



Most POAs last from a definite start time to a specific end time, but they may be created to last for an indefinite period. A POA can be revoked at any time for any reason. There are two ways to revoke a POA:

- By destroying the original document; and/or
- By executing a “Revocation of Power of Attorney” form and sending a certified copy to any financial institution or company where your agent has conducted business on your behalf.

A Guardian can override or revoke a POA.

## What is a Medical Power of Attorney?

A durable Power of Attorney for Health Care is also known as a medical Power of Attorney or health care proxy. It appoints a primary and secondary agent to make decisions about medical care, including end-of-life issues, in the event that the principal is unable to make those decisions.

## What is an Advanced Medical Directive/ Living Will?

A **Living Will** is often called an Advance Directive. A Living Will provides a person’s written instructions on providing or withholding life-sustaining care or procedures when he or she is in a terminal or permanently unconscious condition. It is not required to have a living will to receive medical care.

*A **Living Will** is often called an Advance Directive.*

Many people use a living will, along with a medical Power of Attorney (also called a health care proxy), to make their wishes known about medical treatment and health care.

## What Do I Need to Know about Wills?

If your family member with TBI is your spouse and is unable to make decisions regarding your estate or the care of your children, you may wish to consult your lawyer and make changes to your will.

This may involve naming a guardian for your children and/or assets in the event of your death.

You may also wish to discuss creating a trust as an alternative estate planning tool. The next section describes different types of trusts.

*A trust is a document used in estate planning.*

## What Do I Need to Know about Trusts?

A **trust** is a document used in estate planning. A trust is a written legal agreement between the individual who creates the trust (called the grantor, settlor, or creator) and a trustee, the person or institution who is named to manage the trust assets.

The trustee holds legal title to the assets for the benefit of one or more trust beneficiaries. The ideal trustee has personal knowledge of the grantor and investment expertise. A trustee team—composed of an individual trustee who knows the grantor well and an institutional trustee with investment knowledge—is a workable solution for some people.

There are different types of trusts. The basic categories include:

- A **revocable living trust** is one that can be changed or cancelled at any time.
- An **irrevocable living trust** cannot be changed.
- A **testamentary trust** is one that is irrevocable upon the person's death.

Within these basic categories are a number of types of trusts. Two that may be of interest to families who have a service member/veteran with TBI are:

- A **“special needs” trust** is one that is created by a parent or other family member of a person with a disability who is the beneficiary of the trust. This can be either a living trust or a testamentary trust. The trust may hold cash, personal property, or real property, or can be the beneficiary of life insurance proceeds. The disabled person cannot have any control over these assets.
- A **Qualified Income Trust** (“Miller Trust”) is used in states where there is a limit on the amount of income allowed for Medicaid nursing home eligibility. Some nursing home residents may have retirement incomes at or above the level that disqualifies them for Medicaid, yet do not have enough money to privately pay for a nursing home. Section 1396p of Title 42 of the United States Code permits the creation of an income diversion trust that allows pension, Social Security, and other income to be placed in an irrevocable trust. Upon the death of the beneficiary, the state receives all amounts remaining in the trust equal to the total medical assistance paid by Medicaid on behalf of the beneficiary.





## What Military Resources Can Help Me?

You can find more information about trusts, powers of attorney, and advance medical directives in the *Estate Planning Tool Kit for Military Family & Members* (<https://www.jagcnet.army.mil/852573F600760E8C/0/09DC434FFE528275852573ED004F3B8E?opendocument&noly=1>).

The Armed Forces Judge Advocate General's Corps is comprised of the Army, Navy, Marines, Air Force, and Coast Guard Judge Advocate General's Corps. The Corps provides legal assistance to all active duty service members, reservists on active duty for 30 days or more, and retirees from all branches of the service, and their lawful dependents, based upon available resources and personnel.

To locate a legal assistance attorney, consult the Armed Forces Legal Assistance Web site at <http://legalassistance.law.af.mil/content/locator.php>.

The U. S. Army Judge Advocate General's Corps maintains a Web site to inform military members on personal legal affairs and preventive law. The site (<https://www.jagcnet.army.mil/legal>) contains links to many legal resources.

The American Bar Association has a standing committee on Legal Assistance for Military Personnel (LAMP). Its Web site--<http://www.abanet.org/legalservices/lamp/home.html>--contains useful legal information. It also includes a link to Operation Enduring LAMP which recruits volunteer lawyers across the country to assist military families with legal issues.

## My Legal Documents

*Check off whether or not you have each of the following legal documents for yourself and your service member/veteran with TBI. Do you need this document? If so, who will you contact for help? When?*

Document	Need?	Who Can Help? (Contact Info)	When?
Guardianship			
Power of Attorney			
Medical Power of Attorney			
Living Will			
Trust			
New Beneficiary List on Insurance Policies			

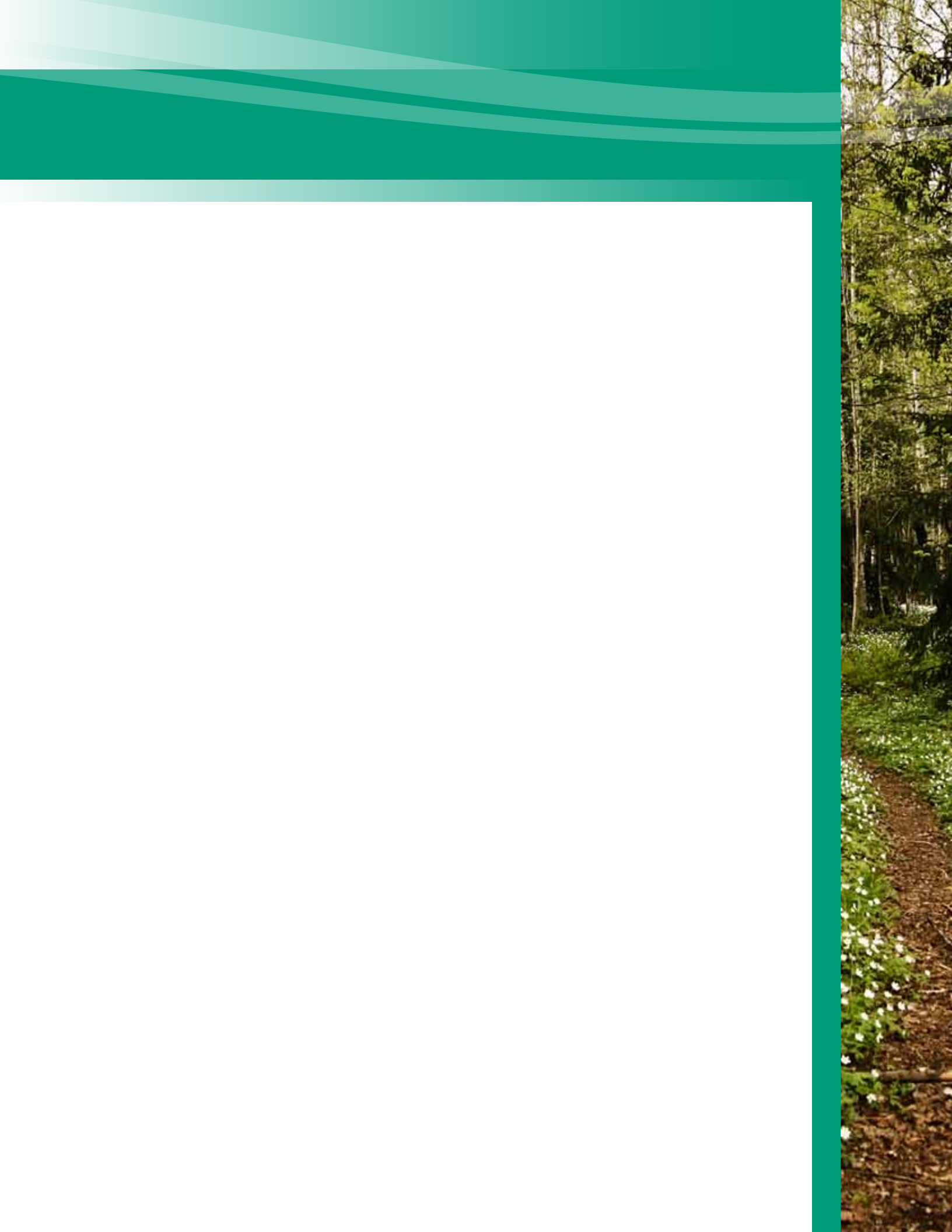


## Journal

*The question below can help you reflect on your experience as a caregiver. You can write your thoughts here, copy this page and add it to your journal if you keep one, or reflect on these questions in your journal.*

*What legal issues most concern you? Why? What do you plan to do to find answers to your questions and concerns?*





## Finding Meaning in Caregiving

May you find peace, compassion, and comfort along the way on your caregiving journey.

*"It's never going to be the same as it was... that's one thing you have a hard time understanding. With a head injury, you grieve over and over and over again, because you realize through these times the things you've lost.*

*On the other hand, you appreciate the things you still have. You know, you really appreciate the little things—I appreciate how you throw a ball now, because it took us forever to teach him to throw a ball. So you really appreciate these things."*

- Denise G.



Your journey as a caregiver may be challenging on many levels. Along the way, you may learn that you care about your service member/veteran with TBI beyond what you realized, and your reserves of strength may surprise you... even when you're tired and lonely.

Take pride in your ability to be caring of another human being. Think about the ways you have changed and grown through your caregiving experience. Finding meaning in your caregiving journey will enlarge your sense of yourself and allow you to use your personal experience to give meaning to others.

Some caregivers find strength in religion or spirituality in the face of the challenges of taking care of a family member with TBI. You may find comfort in your religion or in the peace and beauty of nature. Nourish this part of your life if it is important to you because it may renew your spirit.

Your caregiving experience may change your life and your sense of self. Consider keeping a journal during your caregiving journey. Creating a journal will help you explore your own thoughts and feelings about what's going on in your life.

You may find that you will want to look back on this period in your life at some point in the future. Your journal will be an important guidepost

to what you were thinking and feeling. It may also help you see the changes that happened so slowly that you didn't notice them at the time they happened.

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*"I've done certain things for myself, but it's still hard having my own life at this point. I think my life has changed in some ways for the better. I don't take things for granted, and I feel like my eyes are opened. I can find joy in little things, like possible recovery.*

*Sense of self is hard right now. I told myself I would give it two years because it seemed most of his recovery would be in two years, so I'm doing all this. But I feel like I know my time will come—this is a commitment. It's almost like an investment in my husband. With the progress he's made, I feel like he can be independent and it will be worth it. But I just have to wait a little bit longer. So it gets frustrating, but I keep telling myself that my time will come where it will be more about me."*

- Patty H.

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*"Nobody chooses this. If I could have chosen for him not to be injured, definitely. But you just take what you're given and make the best of it.*

*Other people don't even get to come home. Their families don't even get them back. So we still feel lucky.*

*Initially, the injury is devastating. You don't feel safe anymore. You kind of feel injured yourself. You just don't really have any faith in a lot of things, and you just kind of navigate forward.*

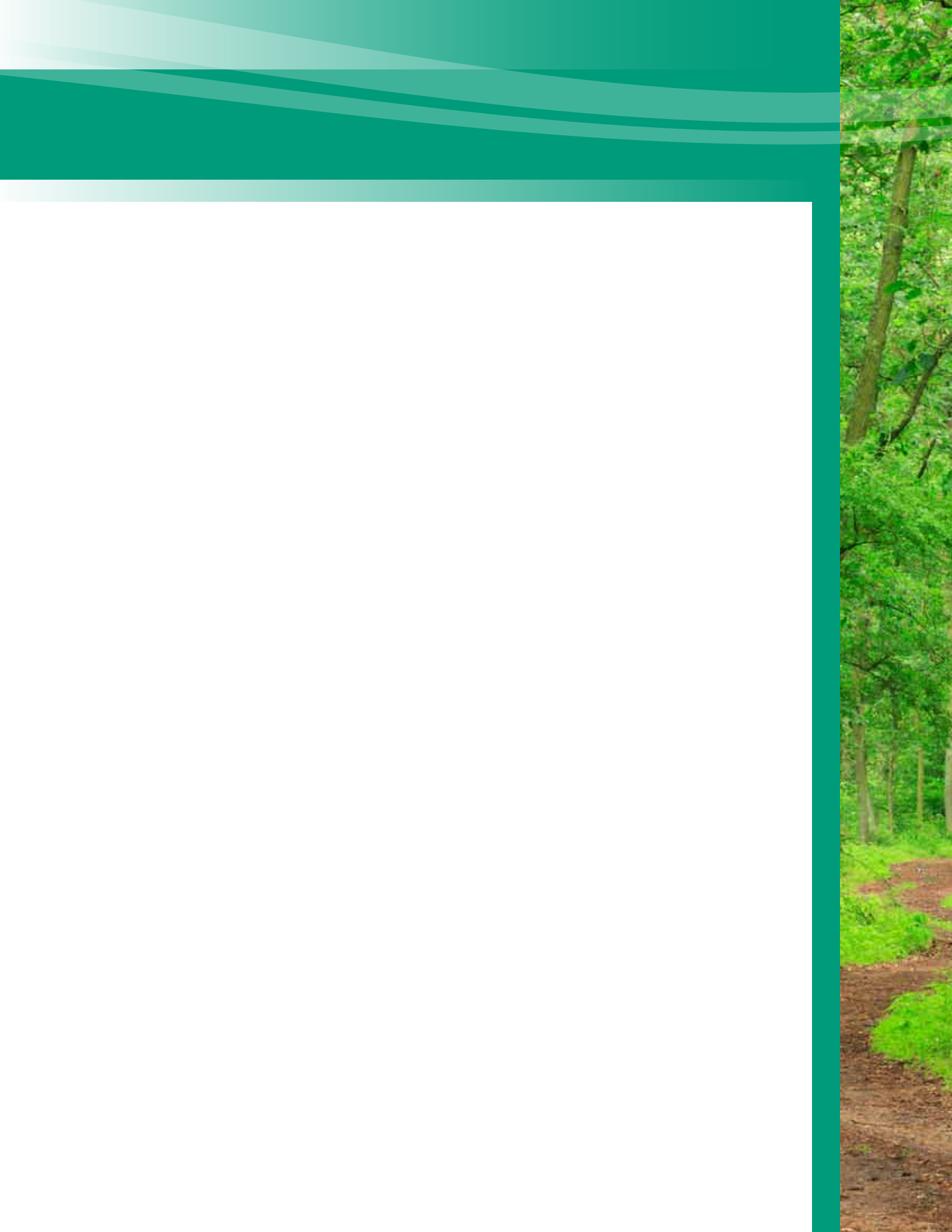
*It is what it is. I would just say to make sure that you're your own advocate and that you don't wait for someone to come and fix you. Make sure that you're getting what you need and that they're doing everything possible for you. It's a long process and nobody wants to be here forever. It takes a long time, especially since he's been on all kinds of deployments.*

*Just navigating the system is hard. You have to keep up with it and take it a day at a time because we don't know what's happening tomorrow, we don't know what's happening next week, but we get to live day to day. We don't know where we're going to be in five years. We don't know where he's going to be in his recovery."*

- Emily S.

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## Resources

These Web sites and phone numbers may be subject to change. Use any of the Internet search engines if you have trouble finding a site.

This appendix contains information about:

The Brain Injury Association of America (BIAA) Chapters

Information and Resources for Caregivers

Military Information Sources

Resources for Helping Children Cope

### BIAA Chapters

#### **BIA of Arizona**

777 E. Missouri Avenue, Suite 101  
Phoenix, AZ 85014  
Phone: 602-508-8024  
Infoline: 602-323-9165  
Fax: 602-508-8285  
Toll Free: 888-500-9165  
E-mail: [info@biaaz.org](mailto:info@biaaz.org)  
Web site: [www.biaaz.org](http://www.biaaz.org)

#### **BIA of Arkansas**

PO Box 26236  
Little Rock, AR 72221-6236  
Phone: (501) 374-3585  
In State: (800) 235-2443  
E-mail: [info@brainassociation.org](mailto:info@brainassociation.org)  
Web site: <http://www.brainassociation.org>

#### **BIA of California**

2658 Mt. Vernon Ave.  
Bakersfield, CA 93306  
Phone: 661-872-4903  
Fax: 661-873-2508  
E-mail: [calbiainfo@yahoo.com](mailto:calbiainfo@yahoo.com)  
Web site: [www.calbia.org](http://www.calbia.org)

#### **BIA of Colorado**

4200 West Conejos Place # 524  
Denver, CO 80204  
Phone: 303-355-9969  
In State: 800-955-2443  
Fax: 303-355-9968  
E-mail: [informationreferral@biacolorado.org](mailto:informationreferral@biacolorado.org)  
Web site: [www.biacolorado.org](http://www.biacolorado.org)

#### **BIA of Connecticut**

333 East River Drive, Suite 106  
East Hartford, CT 06108  
Phone: 860-721-8111  
In State: 800-278-8242  
Fax: 860-721-9008  
E-mail: [general@biact.org](mailto:general@biact.org)  
Web site: [www.biact.org](http://www.biact.org)

#### **BIA of Delaware**

Brain Injury Association of Delaware, Inc.  
32 West Lookerman Street, Suite 103  
Dover, DE 19904  
Toll Free: (800) 411-0505  
Fax: (302) 302-346-2083 (call first)  
E-mail: [biadresourcecenter@cavtel.net](mailto:biadresourcecenter@cavtel.net)  
Web site: [www.biausa.org/Delaware/bia.htm](http://www.biausa.org/Delaware/bia.htm)



**BIA of Florida**

1621 Metropolitan Boulevard, Suite B  
Tallahassee, FL 32308  
Phone: 850-410-0103  
In State: 800-992-3442  
Fax: 850-410-0105  
E-mail: [biaftalla@biaf.org](mailto:biaftalla@biaf.org)  
Web site: [www.biaf.org](http://www.biaf.org)

**BIA of Georgia**

Center for Rehab Medicine  
1441 Clifton Rd. NE #114-A  
Atlanta, GA 30322  
Phone: 404-712-5504  
Fax: 404-712-0463  
Web site: <http://www.braininjurygeorgia.org>

**BIA of Hawaii**

2201 Waimano Home Road, Hale E  
Pearl City, HI 96782-1474  
Phone: 808-454-0699  
Fax: 808-454-1975  
E-mail: [biahi@verizon.net](mailto:biahi@verizon.net)  
Web site: [www.biausa.org/Hawaii](http://www.biausa.org/Hawaii)

**BIA of Idaho**

P.O. Box 414  
Boise, ID 83701-0414  
Phone: 208-342-0999  
In State: 888-374-3447  
Fax: 208-333-0026  
E-mail: [info@biaid.org](mailto:info@biaid.org)  
Web site: [www.biaid.org](http://www.biaid.org)

**BIA of Illinois**

P.O. Box 64420  
Chicago, IL 60664-0420  
Phone: 312-726-5699  
Toll Free: 800-699-6443  
Fax: 312-630-4011  
E-mail: [info@biail.org](mailto:info@biail.org)  
Web site: [www.biail.org](http://www.biail.org)

**BIA of Indiana**

9531 Valparaiso Court, Suite A  
Indianapolis, IN 46268  
Phone: 317-356-7722  
Fax: 317-808-7770  
E-mail: [info@biai.org](mailto:info@biai.org)  
Web site: [www.biausa.org/Indiana](http://www.biausa.org/Indiana)

**BIA of Iowa**

317 East Sixth Street  
Des Moines, IA 50309-1903  
Phone: 515-244-5606  
Toll free: 800-444-6443  
Fax: 800-381-0812  
E-mail: [info@biaia.org](mailto:info@biaia.org)  
Web site: [www.biaia.org](http://www.biaia.org)

**BIA of Kansas and Greater Kansas City**

P.O. Box 413072  
Kansas City, MO 64105  
Phone: 816-842-8607  
In State: 800-783-1356  
Fax: 816-842-1531  
E-mail: [Lliggett@biaks.org](mailto:Lliggett@biaks.org)  
Web site: [www.biaks.org](http://www.biaks.org)

**BIA of Kentucky**

7410 New LaGrange Rd. Suite 100  
Louisville, KY 40222  
Phone: 502-493-0609  
In State: 800-592-1117 x223  
Fax: 502-426-2993  
Web site: [www.biak.us](http://www.biak.us)

**BIA of Maine**

13 Washington Street  
Waterville, ME 04901  
Phone: 207-861-9900  
In State: 800-275-1233  
Fax: 207-861-4617  
E-mail: [info@biame.org](mailto:info@biame.org)  
Web site: [www.biame.org](http://www.biame.org)

**BIA of Maryland**

2200 Kernan Drive  
Baltimore, MD 21207  
Phone: 410-448-2924  
In State: 800-221-6443  
Fax: 410-448-3541  
E-mail: [info@biamd.org](mailto:info@biamd.org)  
Web site: [www.biamd.org](http://www.biamd.org)

**BIA of Massachusetts**

30 Lyman St.  
Westborough, MA 01581  
Phone: 508-475-0032  
In State: 800-242-0030  
Fax: 508-475-0400  
E-mail: [biama@biama.org](mailto:biama@biama.org)  
Web site: [www.biama.org](http://www.biama.org)

**BIA of Michigan**

Director of Programs  
and Services: Cheryl A. Burda  
7305 Grand River, Suite 100  
Brighton, MI 48114-7379  
Phone: 810-229-5880  
In State: 800-772-4323  
Fax: 810-229-8947  
E-mail: [info@biami.org](mailto:info@biami.org)  
Web site: [www.biami.org](http://www.biami.org)

**BIA of Minnesota**

34 13th Avenue NE, Suite B001  
Minneapolis, MN 55413  
Phone: 612-378-2742  
In State: 800-669-6442  
Fax: 612-378-2789  
E-mail: [info@braininjurymn.org](mailto:info@braininjurymn.org)  
Web site: [www.braininjurymn.org](http://www.braininjurymn.org)

**BIA of Mississippi**

P.O. Box 55912  
Jackson, MS 39296-5912  
Phone: 601-981-1021  
In State: 800-641-6442  
Fax: 601-981-1039  
E-mail: [biaofms@aol.com](mailto:biaofms@aol.com)  
Web site: [www.msbia.org](http://www.msbia.org)

**BIA of Missouri**

10270 Page Ave, Suite 100  
St. Louis, MO 63132  
Phone: 314-426-4024  
Fax: 314-426-3290  
In State: 800-377-6442 (MO, IL, KS only)  
E-mail: [info@biamo.org](mailto:info@biamo.org)  
Web site: [www.biamo.org](http://www.biamo.org)

**BIA of Montana**

1280 S. 3rd St. West, Suite 4  
Missoula, MT 59802  
Phone: 406-541-6442  
In State: 800-241-6442  
E-mail: [biam@biamt.org](mailto:biam@biamt.org)  
Web site: [www.biamt.org](http://www.biamt.org)

**BIA of New Hampshire**

109 North State Street, Ste 2  
Concord, NH 03301  
Phone: 603-225-8400  
In State: 800-773-8400  
Fax: 603-228-6749  
E-mail: [mail@bianh.org](mailto:mail@bianh.org)  
Web site: [www.bianh.org](http://www.bianh.org)

**BIA of New Jersey**

825 Georges Road, 2nd Floor  
North Brunswick, NJ 08902  
Phone: 732-745-0200  
In State: 800-669-4323  
Fax: 732-745-0211  
E-mail: [info@bianj.org](mailto:info@bianj.org)  
Web site: [www.bianj.org](http://www.bianj.org)

**BIA of New Mexico**

121 Cardenas NE  
Albuquerque, NM 87108  
Phone: 505-292-7414  
In State: 888-292-7415  
Fax: 505-271-8983  
E-mail: [braininjurynm@msn.com](mailto:braininjurynm@msn.com)  
Web site: [www.braininjurynm.org](http://www.braininjurynm.org)

**BIA of New York**

10 Colvin Avenue  
Albany, NY 12206-1242  
Phone: 518-459-7911  
In State: 800-228-8201  
Fax: 518-482-5285  
E-mail: [info@bianys.org](mailto:info@bianys.org)  
Web site: [www.bianys.org](http://www.bianys.org)

**BIA of North Carolina**

PO Box 10912  
Raleigh, NC 27605  
Phone: 919-833-9634  
In State: 800-377-1464  
Fax: 919-833-5415  
E-mail: [Sandra.farmer@bianc.net](mailto:Sandra.farmer@bianc.net)  
Web site: [www.bianc.net](http://www.bianc.net)

**BIA of Ohio**

855 Grand View Avenue, suite 225  
Columbus, OH 43215-1123  
Phone: 614-481-7100  
Fax: 614-481-7103  
In State: 866-644-6242 ("Ohio BIA")  
E-mail: [Help@Biaoh.org](mailto:Help@Biaoh.org)  
Web site: [www.biaoh.org](http://www.biaoh.org)

**BIA of Oklahoma**

PO Box 88  
Hillsdale, OK 73743-0088  
Phone: 405-513-2575  
E-mail: [brainhelp@braininjuryoklahoma.org](mailto:brainhelp@braininjuryoklahoma.org)  
Web site: [www.braininjuryoklahoma.org](http://www.braininjuryoklahoma.org)

**BIA of Oregon**

2145 NW Overton Street  
Portland, OR 97210  
Phone: 503-413-7707  
In State: 800-544-5243  
Fax: 503-413-6849  
E-mail: [biaor@biaoregon.org](mailto:biaor@biaoregon.org)  
Web site: [www.biaoregon.org](http://www.biaoregon.org)

**BIA of Pennsylvania**

2400 Park Drive  
Harrisburg, PA 17110  
Phone: 717-657-3601  
In State: 866-635-7097  
E-mail: [info@biapa.org](mailto:info@biapa.org)  
Web site: [www.biapa.org](http://www.biapa.org)

**BIA of Rhode Island**

935 Park Avenue, Suite 8  
Cranston, RI 02910-2743  
Phone: 401-461-6599  
Fax: 401-461-6561  
E-mail: [braininjuryctr@biaofri.org](mailto:braininjuryctr@biaofri.org)  
Web site: [www.biapa.org](http://www.biapa.org)



**BIA of South Carolina**

800 Dutch Square Blvd. Suite B-225  
Columbia, SC 29210  
Mailing Address: P. O. Box 21523  
Columbia, SC 29221-1523  
Phone: 803-731-9823  
Toll Free: 800-290-6461 (in-state)  
Fax: 803-731-4804  
E-mail: [scbraininjury@bellsouth.net](mailto:scbraininjury@bellsouth.net)  
Web site: [www.biausa.org/SC](http://www.biausa.org/SC)

**BIA of Tennessee**

151 Athens Way, Suite 100  
Nashville, TN 37228  
Phone: 615-248-2541  
Toll Free: 877-757-2428  
E-mail: [sjohnson@BrainInjuryTN.org](mailto:sjohnson@BrainInjuryTN.org)  
Web site: [www.BrainInjuryTN.org](http://www.BrainInjuryTN.org)

**BIA of Texas**

316 W 12th Street, Suite 405  
Austin, TX 78701  
Phone: 512-326-1212  
In State: 800-392-0040  
Fax: 512-478-3370  
E-mail: [info@biatx.org](mailto:info@biatx.org)  
Web site: [www.biatx.org](http://www.biatx.org)

**BIA of Utah**

1800 S West Temple, Suite 203  
Salt Lake City, UT 84115  
Phone: 801-484-2240  
In State: 800-281-8442  
Fax: 801-484-5932  
E-mail: [biau@sisna.com](mailto:biau@sisna.com)  
Web site: [www.biau.org](http://www.biau.org)

**BIA of Vermont**

P O Box 226  
Shelburne, VT 05482  
Phone: 802-985-8440  
Toll Free: 877-856-1772  
E-mail: [biavtinfo@adelphia.net](mailto:biavtinfo@adelphia.net)  
Web site: [www.biavt.org](http://www.biavt.org)

**BIA of Virginia**

1506 Willow Lawn Drive, Suite 112  
Richmond, VA 23230  
Phone: 804-355-5748  
In State: 800-334-8443  
Fax: 804-355-6381  
E-mail: [info@biav.net](mailto:info@biav.net)  
Web site: [www.biav.net](http://www.biav.net)

**BIA of Washington State**

3516 S. 47th Street, Suite 100  
Tacoma, WA 98409  
Phone: 253-238-6085  
In State: 800-523-5438  
Fax: 253-238-1042  
E-mail: [info@biawa.org](mailto:info@biawa.org)  
Web site: [www.biawa.org](http://www.biawa.org)

**BIA of West Virginia**

PO Box 574  
Institute, WV 25112-0574  
Phone: 304-766-4892  
In State: 800-356-6443  
Fax: 304-766-4940  
E-mail: [biawv@aol.com](mailto:biawv@aol.com)  
Web site: [www.biausa.org/WVVirginia](http://www.biausa.org/WVVirginia)

**BIA of Wisconsin**

21100 Capitol Drive, Suite 5

Pewaukee, WI 53072

Phone: 262-790-9660

In State: 800-882-9282

Fax: 262-790-9670

E-mail: [admin@biaw.org](mailto:admin@biaw.org)

Web site: [www.biaw.org](http://www.biaw.org)

**BIA of Wyoming**

111 West 2nd Street, Suite 106

Casper, WY 82601

Phone: 307-473-1767

Nationwide: 800-643-6457

Fax: 307-237-5222

E-mail: [biaw@tribcsp.com](mailto:biaw@tribcsp.com)

Web site: [www.biausa.org/Wyoming](http://www.biausa.org/Wyoming)



## State Contacts

The following are Brain Injury Community contacts in their respective states. The Brain Injury Association of America lists these contacts for informational purposes only and does not review, support, endorse, or guarantee the information, services or activities of these organizations.

### Alabama

#### **Alabama Head Injury Foundation, Inc.**

3100 Lorna Road, Suite 226

Hoover, AL 35216

Phone: (205) 823-3818

Fax: (205) 823-4544

E-Mail: [charlespriest@bellsouth.net](mailto:charlespriest@bellsouth.net)

Web site: [www.ahif.org](http://www.ahif.org)

You may also contact the Brain Injury Association of America's National Family HelpLine at (800) 444-6443 or [FamilyHelpline@biausa.org](mailto:FamilyHelpline@biausa.org)

### Alaska

#### **Alaska Brain Injury Network, Inc.**

3745 Community Park Loop, Suite 240

Anchorage, AK 99508

888-574-2824 or 907-274-2824

E-mail: [contact@alaskabraininjury.net](mailto:contact@alaskabraininjury.net)

Web site: [www.alaskabraininjury.net](http://www.alaskabraininjury.net)

For any questions regarding service or assistance in Alaska, you may also contact The Brain Injury Association of America's National Family HelpLine at (800) 444-6443 or [FamilyHelpline@biausa.org](mailto:FamilyHelpline@biausa.org)

#### **The Traumatic Brain Injury Resource Directory (TBIRD)**

You may also contact the Brain Injury Association of America's National Family HelpLine at (800) 444-6443 or [FamilyHelpline@biausa.org](mailto:FamilyHelpline@biausa.org)

### Louisiana

#### **Brain Injury Association of Louisiana (BIALA)**

P.O. Box 57527

New Orleans, LA 70157

Phone: 504-619-9989

Toll Free: 1-800-500-2026

Web site: [www.biala.org](http://www.biala.org)

For any questions regarding service or assistance in Louisiana, please contact The Brain Injury Association of America's National Family HelpLine at (800) 444-6443 or [FamilyHelpline@biausa.org](mailto:FamilyHelpline@biausa.org)



### Nebraska

For any questions regarding service or assistance in Nebraska, please contact The Brain Injury Association of America's National Family HelpLine at (800) 444-6443 or [FamilyHelpline@biausa.org](mailto:FamilyHelpline@biausa.org)

### Nevada

For any questions regarding service or assistance in Nevada, please contact The Brain Injury Association of America's National Family HelpLine at (800) 444-6443 or [FamilyHelpline@biausa.org](mailto:FamilyHelpline@biausa.org)

### North Dakota

#### **Open Door Center**

209 2nd Avenue, S.E.

Valley City, ND 58072

Phone: (701) 845-1124

Fax: (701) 845-1175

You may also contact the Brain Injury Association of America's National Family HelpLine at (800) 444-6443 or [FamilyHelpline@biausa.org](mailto:FamilyHelpline@biausa.org)

### South Dakota

**South Dakota Brain Injury Alliance** can be found online at:

[www.braininjurysd.org](http://www.braininjurysd.org)

Please contact: Ron Hoops, President - (605) 395-6655

E-mail: [rmmfarm@nrctv.com](mailto:rmmfarm@nrctv.com)

For information about brain injury resources in South Dakota, you may also contact the Brain Injury Association of America's National Family HelpLine at (800) 444-6443 or [FamilyHelpline@biausa.org](mailto:FamilyHelpline@biausa.org)

## Information and Resources for Caregivers

Organization	Services	Eligibility
Assist Guide Information Services <a href="http://www.agis.com">www.agis.com</a>	Provides information about long-term care and caregiving. Offers a caregiver kit	Anyone
American Red Cross- Family Caregiver Training Program <a href="http://www.redcross.org">www.redcross.org</a>	In-person educational sessions offered at local Red Cross chapters	Anyone
ARCH National Respite Network <a href="http://www.respitelocator.org">www.respitelocator.org</a>	Respite locator helps families locate respite services near them	Anyone
Brain Talk Communities <a href="http://brain.hastypastry.net/forums">http://brain.hastypastry.net/forums</a>	Online forum for support and to learn about community resources	Caregivers for those with neurological disorders
Caregiver.com <a href="http://www.caregiver.com">www.caregiver.com</a> 800-829-2734	Online information and support for caregivers, including those in rural areas	Anyone
Caregivers Marketplace <a href="http://caregiversmarketplace.com">http://caregiversmarketplace.com</a> 800-888-0889	Program that offers cash back on goods and products not typically covered by insurance, such as aids for daily living	Anyone who purchases caregiver supplies
CAREgivinghelp.org <a href="http://www.caregivinghelp.org">www.caregivinghelp.org</a> 773-576-1602	Provides information about caregiving	Anyone
Caring Connection <a href="http://www.caringinfo.org">www.caringinfo.org</a> 800-658-8898 (English) 800-658-8896 (Spanish)	Information about advance care planning, hospice care, and financial assistance from the National Hospice and Palliative Care Organization	Anyone
Daily Strength <a href="http://www.dailystrength.org">www.dailystrength.org</a>	Online support communities covering a variety of topics, including caregiving	Anyone

## Information and Resources for Caregivers

Organization	Services	Eligibility
Easter Seals <a href="http://www.easterseals.com">www.easterseals.com</a> 800-221-6827	Provides adult day services, including medical and social services, to people with disabilities	People with disabilities
Faith in Action <a href="http://www.fianationalnetwork.org">www.fianationalnetwork.org</a> 866-839-8865	Network of interfaith volunteer caregiving programs that may provide help with shopping, cooking, and/or driving	Varies by program
Family Caregiver Alliance (FCA) <a href="http://www.caregiver.org">www.caregiver.org</a> 800-445-8106	A caregiver support organization that provides online information, an online caregiver group, and a state-by-state Help for Caregivers section.	Friends and family caring for adults with cognitive disorders
Share the Care <a href="http://www.sharethecare.org">www.sharethecare.org</a> 646-467-8097	Offers a handbook with guidelines for developing a support network and coordinating care	Anyone
Strength for Caring <a href="http://www.strengthforcaring.com">www.strengthforcaring.com</a>	Online resource and community for family caregivers sponsored by the Caregiver Initiative, Johnson & Johnson	Anyone
Well Spouse Association <a href="http://www.wellspouse.org">www.wellspouse.org</a> 800-838-0879	Provides support to wives, husbands, and partners of the chronically ill and disabled through established support groups across the country	Anyone caring for a chronically ill or disabled spouse

## Military Information Sources

For more information on military resources and service-specific benefits, go to:

- Military OneSource: <http://www.militaryonesource.com> (800-342-9647)
- America Supports You: [www.OurMilitary.mil](http://www.OurMilitary.mil)
- Army Wounded Warrior Program (AW2): [www.aw2.army.mil](http://www.aw2.army.mil) (800-237-1336)



- Air Force Wounded Warrior AFW2:  
<http://www.woundedwarrior.af.mil>
- US Marine Corps Wounded Warrior Regiment:  
<http://www.woundedwarriorregiment.org>
  - Sergeant Merlin German Wounded Warrior Call Center (1-877-USMCWW) (1-877-487-6299)
  - Wounded Warrior Battalion East (910-449-9855)
  - Wounded Warrior Battalion West (1-888-738-7044)
  - Wounded Warrior Injured Support in Landstuhl (1-866-645-8762)
- Safe Harbor (Navy): <http://www.npc.navy.mil/CommandSupport/SafeHarbor> (866-746-8563)
- Disability Benefits for Wounded Warriors through the Social Security Administration: [www.ssa.gov/woundedwarriors/index.htm](http://www.ssa.gov/woundedwarriors/index.htm)
- Defense Centers of Excellence: [www.dcoe.health.mil](http://www.dcoe.health.mil)
- VA Polytrauma System of Care: [www.polytrauma.va.gov](http://www.polytrauma.va.gov)
- American Legion - Heroes to Hometowns:  
[www.legion.org/veterans/h2h/about](http://www.legion.org/veterans/h2h/about)
- Defense and Veterans Brain Injury Center:  
[www.dvbic.org](http://www.dvbic.org)
- Military JobSearch:  
<http://www.militaryspousejobsearch.org/msjs/app>

### Resources for Helping Children Cope

MilitaryOneSource, [www.militaryonesource.com](http://www.militaryonesource.com), has information for families on a wide array of issues.

Sesame Street Workshop has produced videos to help children in military families understand issues related to military service and to help parents communicate effectively with their children about these issues. One video addresses “Changes” that occur when a parent has been injured. You can find these videos at <http://archive.sesameworkshop.org/tlc>.

The National Resource Center at the Virginia Model TBI System has published a book entitled *A Kid’s Guide to Brain Injury* for children 6 to 14. You can find this and other resources at their Web site:  
[www.neuro.pmr.vcu.edu](http://www.neuro.pmr.vcu.edu).

## References/Credits

### Chapter 1

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### Chapter 4

Definition of Compassion Fatigue, Figley, CR. (1995). *Compassion Fatigue*. Brunner-Routledge.

The 13 Item Stress Test, page 27, reprinted with permission from *Getting Better and Better After Brain Injury*, National Resource Center for Traumatic Brain Injury [www.nrc.pmr.vcu.edu](http://www.nrc.pmr.vcu.edu), Virginia Commonwealth University.

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### Chapter 5

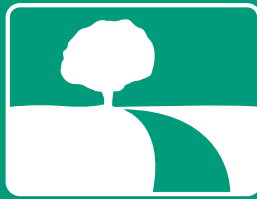
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### Chapter 8

Home Safety Checklist: This checklist was developed by Patricia A. Gentile, MS, OTR/L and Yvette Kearns, OTR/L, Jamaica Hospital Medical Center & Brady Institute for Traumatic Brain Injury. Reprinted with permission.







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